Participant Manual for the WHO Basic ART Clinical Training Course

based on WHO IMAI Chronic HIV Care including ARV Therapy

INTEGRATED MANAGEMENT OF ADOLESCENT AND ADULT ILLNESS

August 2004

World Health Organization  fhi Family Health International  L-TECH
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- Input of materials from MSF (through Alexandra Calmy), MTCT+, and Mildmay Uganda is also gratefully acknowledged. They are part of the training working group but were unable to attend the December 2003 working meeting. Line drawings by Jovan Bahizi, Uganda.

Revised after the Masaka and Hoima, Uganda trainings.

Please ask for the most up-to-date version of this course prior to use and provide feedback, so we can continue to improve both the IMAI guidelines and these training materials. Work is ongoing to translate into several languages. Please send comments to goves@who.int or 3by5help@who.int.

This is the participant training manual which includes written exercises and references photos in the IMAI Photobooklet. Participants should also have copies of:

4 IMAI guideline modules (these can be downloaded from www.3by5.org/capacity):
- Acute Care, WHO/CDS/IMAI/2004.1
- Chronic HIV Care with ARV Therapy WHO/CDS/IMAI/2004.2
- General Principles of Good Chronic Care WHO/CDS/IMAI/2004.3
- Palliative Care WHO/CDS/IMAI/2004.4
- Rev 1
- Other communication and clinical aids:
  - Flip chart for educating patients (HIV basics, ART, positive living, prevention)
  - Copies of 2-sided recording forms (Annex A):
    - Front: Clinical review; assess pregnancy/FP, TB, functional status, clinical stage
    - Back: 7 requirements to initiate ART at first-level facility

HIV Care/ART card (Annex B)
Expert patient cases for each skill station session (Annex C)
Patient treatment cards (Annex D)
Photobooklet

Additional facilitator course materials:
- Course Director/Facilitator Guide
- Laminated wall charts
- Cards for card sorts
- Expert patient training guide
- Clinical training videos
# Participant Manual for the WHO Basic ART Clinical Training Course

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**For on-site visit after training:**

| Chapter 19 | Caring for health workers and post-exposure prophylaxis                                                                                                                                             |      |

**Annexes:**

- **Annex A**: Clinical Review Form
- **Annex B**: HIV Care/ART Card
- **Annex C**: Introduction to the Skill Stations and Health-worker Casebook
- **Annex D**: Patient Treatment Cards (for each first-line regimen)
Introduction to IMAI

Lack of access to ARV drugs has been declared a global health emergency. Universal access to ARV therapy is considered a human right and an initial target has been set by WHO of ensuring that three million people are on treatment by the end of 2005.

During the last 20 years, Ministries of Health, NGOs and private providers have been working in collaboration with WHO, UNAIDS, bilateral donors, and other local and international partners to establish comprehensive care programmes for HIV infected people. ART is now being added to this in certain health units. We hope that this training course, based on a country (or project) adaptation of the IMAI Chronic HIV Care with ARV Therapy, will contribute to this, both in the district hospital outpatient clinic and down to ART delivery through health centres at community level.

What is IMAI?

IMAI is the Integrated Management of Adolescent and Adult Illness. These simplified and standardized WHO guidelines support the delivery of ARV therapy within the context of primary health care, based at first-level health facilities or in district outpatient clinics. The guidelines are based on the standardization and simplification of ARV regimens presented in Scaling Up Antiretroviral Therapy in Resource-Limited Settings. IMAI provides tools (standardized guidelines and training courses to teach these guidelines). The modules are for country adaptation and use in their efforts to achieve their 3 by 5 target and eventually universal access to ART.

The guideline modules cover Chronic HIV care with ARV Therapy, Acute care (including the management of opportunistic infections and when to suspect HIV, linking to testing and counselling), Palliative Care (symptom management at home), and General Principles of Good Chronic Care (to support the health system transition from acute to chronic care). Each module can be used alone or as an integrated package. The pocket-size guideline modules are intended to be used both as learning aids (during this training course) and as job aids (for reference during clinical care). The modules are cross-referenced between each other; however, other national guidelines can be substituted if necessary. See Annex A for a short description of the 4 IMAI modules that are relevant to the continuum of care for HIV. Course participants will be given all 4 guideline modules and will learn to use them. The course focuses on the clinical part of chronic HIV care including ARV therapy guideline module.

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**Target groups for this Basic ART Clinical Training course**

This course is intended for first-level facility health workers who work in a district outpatient clinic or in peripheral health centres and clinics, in rural or urban areas, in resource-constrained settings. We have divided the training to support the chronic HIV care including ART into two short (five day) courses - this clinical training course and a counselling course.

Clinical training in the use of these simplified guidelines will hopefully provide an efficient introduction to chronic HIV care and to ART. This will allow key tasks to be shifted from doctors to nurses, clinical officers, medical aids and other multipurpose health workers within a clinical team. The goal is efficient quality ARV therapy (ART) based on a solid chronic care model.

Medical officers or doctors can also go through this course more rapidly for an introduction to chronic HIV care and ART and to make them thoroughly familiar with the care provided by others on the clinical team, which they will need to supervise. This course would then need to be followed by more advanced ART and OI training.

The Basic ART Aid Training Course addresses triage, patient education, and psychosocial support, prevention, and adherence preparation and support guidelines. These guidelines have been designed so they can be implemented by PLHA and other lay providers working on the clinical team². An important source for the increase in human resources required to rapidly expand access to ART can come from PLHA and other community members who both join clinical teams and support treatment and other care in the community.

Management of common opportunistic infections is important prior to starting ART. An additional short (two day) course is available to prepare first-level facility health workers to recognize and treat key common opportunistic infections in preparation for ART. It is possible that you already know how to provide acute care and to manage opportunistic infections as an outpatient and to refer when necessary. If this is the case, you may be able to skip the Opportunistic Infection/Acute Care course and take only this course that teaches Chronic HIV Care with ARV Therapy.

Symptom management (palliative care) remains important throughout acute and chronic HIV care, during ART, and if ART needs to be stopped. This is summarized in the Palliative Care module. These guidelines prepare the health worker to teach patients, families and community caregivers to provide effective care at home, using the Patient Self-Management and Caregiver Booklet. A short (three day) course is available.

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² This is different from a Community Health Worker who is a trained lay provider based in the community, not based on the clinical team in the health facility.
Chapter 1: Introduction to Chronic HIV Care including ARV Therapy

Learning objectives

By the end of this chapter you should be able to understand:

- the difference between acute and chronic care;
- the general principles of good chronic care.

Comprehensive care for people living with HIV/AIDS requires both clinical care based at the health facility and home-based care involving the patient, family and friends, community health workers, other community-based caregivers, traditional healers, and community-based organizations, NGOs and FBOs. The sequence of clinical care presented on pages H8 to H9 of the Chronic HIV Care with ARV Therapy module is centred around community care and treatment support. This course concentrates on clinical care, which is an important component of comprehensive care but not the only one. The IMAI ART Aid course prepares PLHA, nursing assistants or nurses to provide patient education, psychosocial support, and adherence preparation and support within the clinical team. Some of the IMAI communication and patient education material can also be used for community treatment preparedness and other training that occurs in the community.

The Chronic HIV Care with ARV Therapy guidelines start with a positive HIV test and the patient accepting care. For some patients, there will be a gap between testing positive and coming to a health facility for care.

Acute and chronic HIV care and prevention

To improve the comprehensive care of PLHA at health centres and at the district or hospital outpatient clinic, it is important to be able to provide both good acute and chronic care and prevention at the health facilities and to link with home-based care.

Think about the care that you provide now in your clinic or health centre. Is it mostly acute care or chronic care? Most care that we deliver is usually acute care. Acute care includes the management of the common illnesses that are problems for adolescents and adults. These include common bacterial infections, skin, neurological and mental health problems. In countries with a high prevalence of HIV infection, more and more of these acute problems are due to opportunistic infections based on immunodeficiency from the HIV infection. HIV infection causes a chronic disease but if we only care for the patient during episodes of acute illness, then we are only providing acute care. We are not yet providing good chronic care.

Because most health care systems developed in response to acute problems, they are designed to address urgent health care needs and to diagnose, relieve symptoms, and anticipate a cure. Health care for chronic conditions is different from health care for acute problems.
To better manage chronic conditions including HIV/AIDS, health care needed to be organized and delivered in a different way. Acute care will always be necessary (even chronic conditions have acute episodes), but at the same time health care must be able to care for long-term health problems.

Introduction to the General Principles of Good Chronic Care

Good chronic care recognizes the fact that the patient must understand and learn to manage his or her own chronic condition. HIV infection and its slow progression to AIDS require much education and support to give patients the skills to self-manage (manage their own condition). Although the clinical team and others at home and in the community can help, it is the patient that needs to learn to cope with their infection, to disclose to those that they trust in order to get further help, to learn to practice prevention and positive living, and to understand and use prophylaxis and ART and other treatments. This requires much education and support but the results for the patient are important.

The following principles can be used in managing many diseases or risk conditions, including HIV/AIDS. We will learn about these gradually throughout this course. (They will appear in various chapters of this manual. The module General Principles of Good Chronic Care also has explanations and good examples to help you learn the 5 A’s.)

1. Develop a treatment partnership with your patient
2. Focus on your patient’s concerns and priorities
3. Use the 5 A’s—Assess, Advise, Agree, Assist, Arrange
4. Support patient self-management
5. Organize proactive follow-up
6. Involve “expert patients,” peer educators and support staff in your health facility
7. Link the patient to community-based resources and support
8. Use written information - registers, Treatment Plan, and treatment cards - to document, monitor, and remind
9. Work as a clinical team
10. Assure continuity of care.

Research has shown that when patients receive this kind of health care, they do better.

These principles will be explained in relevant sections to follow.

A general principle of good chronic care:

1. Develop a treatment partnership with your patient

What is a partnership? A partnership is an agreement between two or more people to work together in an agreed way toward an agreed goal.

For good chronic care, the partnership is between the health worker (or clinical team) and the patient. In a partnership both parties share responsibility for the agreement. Each partner knows what role he or she plays in the partnership. Partners treat each other with respect. One partner does not have all the power.

Examples of a partnership:
A general principle of good chronic care:
2. Focus on your patient's concerns and priorities

Often we focus only on the obvious signs or symptoms of illness and may miss the real reason that the patient came to the clinic. It is important to find out why the patient has come and make sure that this is addressed.

A general principle of good chronic care:
3. Use the 5 A's—Assess, Advise, Agree, Assist, Arrange

The 5 As are a key part of the good chronic care. They are a series of steps to use in caring for patients.

1. ASSESS

Currently most of you are familiar with the process of assessing for the patient's symptoms and signs, classifying (or diagnosing) the illness, and deciding what treatments to recommend. In IMCI, this is called Assess-Classify-Identify Treatments. Assess includes asking what the problem is, listening to the answer, asking further questions, then examining the patient by looking, listening (for example, to hear a wheeze) and feeling, as appropriate for the patient's symptoms.

In acute care, we usually assume that the patient’s goal for the visit is treatment for their main symptoms. It is common to skip over assessing behavioural risk factors or to ask about how the patient is managing their chronic condition. Sometimes we even miss the real reason the patient came to the clinic.

For good chronic care, this step needs to be expanded. In the General Principles of Good Chronic care module, read through the bullet points under ASSESS for both the initial visit and the follow-up visit in General Principles of Good Chronic Care. Try out the suggested wordings for questions in the General Principles of Good Chronic Care guideline module.
2. ADVISE

This includes recommending the treatments to the patient, educating the patient, and preparing the patient for self-management. It is important to discuss the options, not to just tell the patient what to do. It is also important to evaluate how ready the patient is to adopt the treatment and to ask checking questions to make sure that they have understood. (If you do not know how to ask a checking question, tell your facilitator. We will practice this later.)

Try out some of the suggested wordings for questions.

3. AGREE

Agree means that the patient understands, wants and agrees to the treatment plan. This is a step we often skip!

It may be logical to skip this step during emergency care for trauma or a very sick patient. They have come (or been brought) for care and are too sick for a discussion or to make a choice. For young children needing acute care, we try to tell them what is happening but we often do not ask for their agreement (and would still treat them even if they screamed “no” which they often do).

However, most care is not an emergency and we are learning about how best to provide care for adults. For chronic care, AGREE is the key step in the process since it is the basis for forming a partnership with the patient and supporting good patient self-management.

4. ASSIST

This includes treatments (medication and other treatments), advice and counselling, but also help that you can provide the patient in terms of skills to carry out the treatments or to overcome barriers. An important way to assist the patient is to get other help, by linking to available support in the community or to peer support groups or involving someone to help support them in their treatment.

Usually we (and the patients) focus only on the pills or the injection. There is much more that is needed than this for good chronic care, especially for life-long treatment like ARV therapy.

Even the best plans for treatment often run into problems. When the patient returns, they may need more assistance to solve problems and overcome obstacles.

We often assist the patient only with treatments and skip other ways of assisting that may be as important.

5. ARRANGE

A definite follow-up, scheduling a group appointment, arranging how the medication can be picked up on the next visit, and recording what happened on the visit are all parts of arrange.

Stop here to discuss with group how you already use the 5 As and to consider how they could help you both in your individual encounters with patients and as a clinical team.
A general principle of good chronic care:
4. Support patient self-management

Whenever talking about how the patient can have his/her needs met and who can support him/her, health workers should always try to leave the patient as much in charge of his or her own care as possible. This is very important for adolescents and adults. A patient with a chronic condition such as HIV/AIDS has a vital role in the management of his/her own care. This is called SELF-MANAGEMENT.

Self-management means the patient taking responsibility for their own health care.

Self management recognizes that the patient takes responsibility for the daily treatment of their condition.

The patient takes responsibility for taking medication (such as cotrimoxazole or ARV drugs). Everyday he or she makes choices about their diet, exercise, and other lifestyle issues that protect or damage their health (when the patient living with HIV make choices to protect their health, this is often called positive living). He or she makes choices on how to practice safer sex, use condoms, and prevent sexually transmitted infections and unintended pregnancies. (This is called prevention.)

The care team helps the patient understand their options and the consequences of their decisions. The patient is the one who, on a daily basis, makes lifestyle choices and chooses to follow the plan of care.

The patient is responsible for doing what is recommended by the care team.

Patients need to be educated, motivated and supported to take care of themselves. This gives them a better sense of control and makes them feel better about their situation. It has been shown that this approach makes them more successful in caring for themselves.

Promoting self-management includes developing a relationship between the care team and the patient that the patient trusts and believes in.

Self-management is particularly important when it comes to ART. We will learn about this later in the course.

Combining acute care, chronic care, palliative care/symptom management, and prevention.

If the patient is found to be HIV positive, he or she should be offered chronic HIV care. Chronic HIV care is in addition to acute care for any illness they have today or when they return for regular follow-up. PLHA need both acute care (like any adult) and chronic HIV care, including ARV therapy when they are ready for it.

Patients also need palliative care or symptom management, so that the suffering of acute infections and the side effects of medications (including ARV therapy) can be managed well. Note that palliative care includes managing symptoms during both acute and chronic illness. It is not just for end-of-life care! Look through the Palliative Care module to familiarize yourself with what is covered there.
Prevention needs to be integrated throughout both acute and chronic HIV care. Expanding the treatment options for HIV allows us to also expand our prevention interventions. We will discuss this in Chapter 13.

The IMAI Acute Care guidelines will help you provide acute care for adults, using a similar process to the one used for the integrated management of childhood illness (IMCI).

### A general principle of good chronic care:

5. **Work as a clinical team**

Working as a clinical team to deliver both acute and chronic HIV care including ART

Providing good chronic care requires teamwork. To be able to deliver ART, we need to form a clinical team that includes a nurse, clinical officer, an ART Aid (for education, psychosocial support, adherence preparation and support), and a medical officer or doctor. This team may work together differently depending on where they are located.

In the district outpatient clinic, the whole clinical team can work together in the same clinic. They can consult with each other easily every day. The doctor or medical officer needs to be familiar with the IMAI Chronic HIV Care Including ART but also needs to be guided by other national and WHO ART guidelines for senior clinicians and trained by other courses. The MD/MO will need additional training to be able to supervise, consult, review cases, and to take on overall clinical responsibility for the ART and chronic HIV care delivered by the clinical team.

At a health centre without a doctor or medical officer, the nurse, clinical officer and counsellors will need to stay in communication with the MD/MO on their clinical team, by referral and back-referral and by communication. To allow access to ART through health centre-based clinical teams outside the district towns, it will be necessary to consult by mobile phone, landline or radio when problems arise. It will also be important to arrange for visits by the MD/MO to the health centre. These are essential to reduce the number of referrals. Although some referrals are essential, referral needs to be kept to a reasonable proportion of cases to be practical.

In illustration on the next page, the same MD or MO would be working both on the clinical team in the district clinic (A) and on a clinical team with the nurse, clinical officer and counsellor at a peripheral health centre (B). We will learn more about how a clinical team can operate at the end of this course.

You will now watch some role-play exercises with your facilitator and an expert patient-trainer.
A Clinical Team at the District

MD, MO

RN, Clinical Officer

ART Aid: PLHA, other lay providers on team or nurse assistant

Supervise clinical care; respond to consults, accept referrals, refer back; more advanced ART and OI training

Basic ART Clinical Training, based on IMAI Chronic HIV Care; Acute Care/OI training.

District ART Clinic/Hospital

MD, MO

RN, Clinical Officer

Consult, refer, back-refer, visit; Good communication

Clinical team

B Health Centre

*. ART Aid: PLHA, other lay providers on team or nurse assistant

CLINICAL TEAM
Chapter 2: Introduction to HIV/AIDS and opportunistic infections

Learning objectives

By the end of this chapter you should be able to:

- describe the progression of HIV/AIDS and the difference between HIV and AIDS;
- describe the impact of HIV on the immune system;
- recognize the common opportunistic infections required for clinical staging and for initiation of ART;
- learn to refer to the IMAI Acute Care guideline module or national clinical guidelines for guidance on clinical problems;
- understand the clinical stages of HIV/AIDS and classify patient cases in the appropriate clinical stage;
- understand the relationship between HIV and tuberculosis;
- describe and recognize atypical presentations of TB in HIV/AIDS.
HOW HIV ATTACKS OUR HEALTH

Look first at Figure 1

1. The CD4 cell is a kind of white blood cell. The CD4 is the friend of our body.

2. Problems like cough try to attack our body, but the CD4 fights them to defend the body, his friend.

3. Problems like diarrhoea try to attack our body, but the CD4 fights them to defend the body.
4. Soon, CD4 loses its force against HIV.

5. The CD4 notices he cannot defend himself against HIV!

6. Soon, CD4 loses its force against HIV.
In the end, the body is so weak, that all diseases can attack without difficulty.

CD4 loses the fight. The body remains without defence.

Now, the body is all alone, without defence. All kinds of problems, like cough and diarrhoea take advantage and start to attack the body.

In the end, the body is so weak, that all diseases can attack without difficulty.
Every healthy person has a strong body defence, to defend the body against diseases. This defence system is called the immune system. The white blood cells play an important role to defend the body against all kinds of diseases. Lymphocytes are a type of white blood cell.

The CD4 cell is a special type of lymphocyte with a marker on its surface called CD4.

HIV attacks mostly these CD4 cells. This is why the number of CD4 cells is a good way of checking how much of your defence is still working.

When a person gets infected with the HIV, the virus will start to attack his/her immune system.

During the first years, the immune system—although weakened a bit by the HIV virus—still functions quite well. The infected person will have no symptoms, or only minor symptoms, like skin diseases, a little loss of weight, repeated sinusitis. A lot of people do not know they are HIV+ at this stage.

After several years, the person’s immune system will be very weak, s/he is vulnerable to diseases that s/he could normally fight off.

These diseases are called opportunistic infections because they take advantage of a weakened immune system to cause disease.

Usually, it takes around 7-10 years after infection before the person becomes very sick (AIDS), if s/he is not taking antiretroviral therapy (ART).
**Figure 2: Ways of explaining the evolution of HIV/AIDS to patients**

**Legend:**
- CD4 cells
- HIV

**Beginning:** skin diseases, chronic
minor loss of weight...
problems,
other opportunistic infections.

**After 5-10 years:** diarrhoea, brain
other opportunistic infections.

**As the CD4 level declines, the risk of getting opportunistic infections increases.**

People with a good immune system have CD4 counts between 450 and 1500 cells/mm³. In general, we can say:

When the number of CD4 has decreased below 450 cells/mm³, the person will start to have some opportunistic infections.

When the CD4 has decreased below 200 cells/mm³, the person will have very serious opportunistic infections.

**OPPORTUNISTIC INFECTIONS WE NEED TO RECOGNIZE AND TREAT IN ORDER TO DO CLINICAL STAGING AND TO START ART**

**Persistent generalized lymphadenopathy (PGL)**
PGL is a chronic swelling of the lymph nodes in at least 2 areas of the body for 3 months or longer. It is common in the head, neck and underarm areas.

Look at photo A.
Skin problems

You are probably already familiar with many of these from your clinical work. Look at the photos referred to below. Also look at pages 43 to 44 of the Acute Care module. This describes some of the skin problems associated with HIV infections.

Itching rash—these include:

**Seborrhoea**: scaly skin eruption on the border between face and hair and side of the nose or chest. These are often greasy scales and redness.

Look at photo C

**Prurigo**: itchy skin eruption on the arms and legs. Often there are small papules and scratch marks. They may leave dark spots with light centres.

Look at photo D

**Herpes Zoster**: common on the chest, but also occurs on a leg, arm or the face. The vesicles are in only one area on one side of the body. There is intense pain. Sometimes the pain continues after the lesions heal. The pain is often a shooting pain.

The blisters can turn into lesions and later into crusts. They may be haemorrhagic (bloody). Generally it takes 2-3 weeks before healing. There is often scarring.

Herpes zoster is a sign of clinical stage 2.

Look at photo E

**Mouth/throat and oesophagus problems**

The organism called Candida can cause several conditions—sores at the corners of the mouth, oral thrush, or oesophageal infection. The same organism also causes vaginal candidiasis.

**Angular cheilitis**

Candida can cause small chronic sores or cracks around the lips, often at the corners of the mouth. These are called angular cheilitis. This occurs early in HIV infection, in stage 2.

Look at photo B
Recurrent mouth ulcers

Look at photo F

**Oral thrush**

White patches from candida can be removed. Sometimes they can appear mostly as red patches. Oral thrush is a sign of clinical stage 3.

Look at photo G

**Oesophageal thrush**

Patients who have the white patches of oral thrush AND who have severe pain on swallowing may have oesophageal thrush.

Oesophageal thrush is a serious infection since it can prevent the patient from eating. Oesophageal thrush also indicates more immune suppression than oral thrush only and is a sign of clinical stage 4. If the patient has so much pain that he or she cannot swallow, this is Severe Oesophageal Thrush. This patient needs to be referred to the hospital if you cannot get the patient to swallow the fluconazole tablet. Look at the classification table on page 21 of the *Acute Care* module for the distinction in severity between Severe Oesophageal Thrush, Oesophageal Thrush and simple Oral Thrush. The most severe condition is at the top.

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<th>CLASSIFY AS:</th>
<th>TREATMENTS:</th>
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<td>▪ Not able to swallow</td>
<td>SEVERE OESOPHAGEAL THRUSH</td>
<td>Refer to hospital If not able to refer, give fluconazole</td>
</tr>
<tr>
<td>▪ Pain or difficulty in swallowing</td>
<td>OESOPHAGEAL THRUSH</td>
<td>Give fluconazole Give oral care Follow up in 2 days Consider HIV-related illness (p.54)</td>
</tr>
<tr>
<td>▪ White patches in mouth and Can be scraped off</td>
<td>ORAL THRUSH</td>
<td>Give nystatin or miconazole gum patch Give oral care Consider HIV-related illness (p.54)</td>
</tr>
<tr>
<td>▪ White patches on side of tongue and Cannot be scraped off Painless</td>
<td>ORAL (HAIRY) LEUKOPLAKIA</td>
<td>No treatment needed Consider HIV-related illness (p.54) Instruct in oral care</td>
</tr>
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</table>

**Oral hairy leukoplakia**

Finer white patches on the side of the tongue which cannot be removed are called oral hairy leukoplakia. These can appear as white vertical lines on the lateral surface of the tongue. This is different from candida and does not need to be treated with antifungals. However, oral hairy leukoplakia (like oral thrush) is a sign of clinical stage 3.

Look at photo H
Pulmonary TB
This should be suspected based on chronic cough, fever, or sweating (often at night), loss of appetite, weight loss, sometimes chest pain (see page 25). For clinical staging, pulmonary TB should have been diagnosed based on positive TB sputums (smear positive) or smear negative pulmonary TB can be diagnosed by the district clinician.

HIV wasting syndrome
Patient is extremely thin with chronic fever and/or chronic diarrhoea.

The clinical staging chart that follows (and appears in section 3.4 of the Chronic HIV Care module) summarizes how these various opportunistic infections indicate the clinical stage of the patient.

If the patient has a sign in more than one clinical stage, the patient's stage is the highest clinical stage where there is a sign.

WHO CLINICAL STAGES

The WHO clinical staging system will help you to estimate the degree of immune deficiency your patient has.

A patient having only symptoms of WHO clinical stage 1 or 2 usually does not have a very serious immune deficiency. Patients who have signs and symptoms of WHO stage 3 or 4 usually have serious immune deficiency: they do not have a lot of CD4 cells left.

Certain conditions need a diagnosis by a doctor or medical officer and should be referred for appropriate diagnosis and treatment. These conditions are marked with an asterisk * in the clinical staging table.
Summary of the Signs and Symptoms for WHO Adult HIV Clinical Stages

<table>
<thead>
<tr>
<th>Symptoms/signs</th>
<th>WHO Clinical Stage 1 Asymptomatic</th>
<th>WHO Clinical Stage 2 Mild Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>No symptoms or only:</td>
<td></td>
<td>✧ Weight loss 5-10%</td>
</tr>
<tr>
<td>✧ Persistent generalized lymphadenopathy: multiple small painless lymph nodes (Photo A)</td>
<td></td>
<td>✧ Sores or cracks around lips (angular cheilitis): small lesions at the corners of the mouth (Photo B)</td>
</tr>
<tr>
<td></td>
<td>✧ Seborrhoea: scaly skin eruption on the border between face and hair and side of the nose (Photo C)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✧ Prurigo: itchy skin eruption on the arms and legs (Photo D)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✧ Herpes zoster: painful blisters on a region of 1 side of the body, face, or extremities (Photo E)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✧ Recurrent upper respiratory infections: repeated throat infections, sinusitis, or ear infections</td>
<td></td>
</tr>
<tr>
<td></td>
<td>✧ Recurrent mouth ulcers: (Photo F)</td>
<td></td>
</tr>
<tr>
<td>WHO Clinical Stage 3</td>
<td>Moderate Disease</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>------------------</td>
<td></td>
</tr>
<tr>
<td>❖ Weight loss &gt;10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>❖ Oral thrush:</td>
<td>white patches covering areas in the mouth</td>
<td></td>
</tr>
<tr>
<td>❖ Oral hairy leukoplakia:</td>
<td>nonpainful, white vertical lines on the side of the tongue, which cannot be scraped off</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Photos G, H)</td>
<td></td>
</tr>
<tr>
<td>❖ More than 1 month:</td>
<td><strong>Diarrhoea:</strong> sometimes intermittent</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Unexplained fever:</strong> sometimes intermittent</td>
<td></td>
</tr>
<tr>
<td>❖ Severe bacterial infections:</td>
<td>pneumonia, muscle infection, etc.</td>
<td></td>
</tr>
<tr>
<td>❖ Pulmonary TB</td>
<td></td>
<td></td>
</tr>
<tr>
<td>❖ TB lymphadenopathy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>❖ Acute necrotizing ulcerative gingivitis/periodontitis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>WHO Clinical Stage 4</th>
<th>Severe Disease (AIDS)</th>
</tr>
</thead>
<tbody>
<tr>
<td>❖ HIV wasting syndrome:</td>
<td>extremely thin with chronic fever and/or chronic diarrhoea</td>
</tr>
<tr>
<td>❖ Oesophageal thrush:</td>
<td>severe pain when swallowing</td>
</tr>
<tr>
<td>❖ More than 1 month:</td>
<td><strong>Herpes simplex ulcerations:</strong> large and chronic painful wounds on the genitals and/or anus</td>
</tr>
<tr>
<td></td>
<td>(Photo J)</td>
</tr>
<tr>
<td>❖ Lymphoma*:</td>
<td>(Photo K)</td>
</tr>
<tr>
<td>❖ Kaposi’s sarcoma:</td>
<td>dark (purple) lesions on the skin and/or mouth, eye, lungs, intestines, often accompanied by a hard oedema</td>
</tr>
<tr>
<td></td>
<td>(Photo L)</td>
</tr>
<tr>
<td>❖ Invasive cervical cancer*:</td>
<td>(Photo M)</td>
</tr>
<tr>
<td>❖ Pneumocystis pneumonia*:</td>
<td>severe pneumonia with shortness of breath on exertion and dry cough</td>
</tr>
<tr>
<td>❖ Extrapulmonary TB*:</td>
<td>for example, in the bone or meningitis</td>
</tr>
<tr>
<td></td>
<td>(Photo N)</td>
</tr>
<tr>
<td>❖ Cryptococcal meningitis*:</td>
<td>meningitis which can present without neck stiffness</td>
</tr>
<tr>
<td>❖ Toxoplasma brain abscess*</td>
<td></td>
</tr>
<tr>
<td>❖ Visceral leishmaniasis*</td>
<td></td>
</tr>
<tr>
<td>❖ HIV encephalopathy*:</td>
<td>significant neurological impairment interfering with independent functioning and not due to other cause, will sometimes improve on ART</td>
</tr>
</tbody>
</table>

Conditions marked with an asterisk * require a clinician diagnosis -- this can be from records of a previous hospitalization.

Muscle infection, pneumocystis or any other severe pneumonia, toxoplasma, cryptococcal meningitis, and extrapulmonary TB are all infections which should be referred for hospital diagnosis and treatment.
EXERCISE 2-1

During the training course, you will receive pictures of the different diseases. A big poster with the clinical stages will be put in front of the class. You will be invited to stick your picture in the appropriate place on the poster. Clinical staging can be easy when we learn it this way.

EXERCISE 2-2

Write down the clinical stage these patients are in. We will correct the exercises in the class afterwards.

1. An extremely thin HIV+ patient has chronic fever for 3 months.

________________

2. An HIV+ patient with pulmonary tuberculosis and purple lesions on the skin of the left leg, with oedema of the leg.

________________

3. An HIV+ patient with oral thrush and intermittent diarrhoea for 1 month.

________________

4. An HIV+ patient with tuberculosis of the cervical lymph nodes.

________________

5. An HIV+ patient with big abscesses of the skin which extend to the muscle, with some yellow pus coming out of some of them.

________________
RELATION BETWEEN HIV AND TUBERCULOSIS (TB)

This topic is included in the manual, because HIV greatly increases the risk of an individual developing tuberculosis disease.

HIV greatly increases the risk for TB disease
It is common to be infected with the TB germ (mycobacterium tuberculosis) but not to have TB disease. In patients with AIDS, TB is a common cause of death, because 'sleeping' or latent TB can be reactivated due to a weak immune system. With HIV, it is common to have the two diseases together.

What is TB?
Symptoms of pulmonary TB are persistent cough that does not or weakly responds to antibiotics, fever, and loss of weight.

TB can also manifest outside the lungs, in lymph nodes or extra-pulmonary TB in the bones, kidneys, abdomen, and central nervous system. Extrapulmonary TB In these organs can be more serious than in the lungs. Extrapulmonary TB is a stage 4 condition whereas pulmonary TB and TB lymphadenopathy are stage 3 conditions.

How is TB spread?
Coughing spreads the TB germ from the lungs to the air. Now, persons sharing the room with a TB infected person can inhale the TB germ.

Of all persons infected with TB after inhaling the TB bacilli, only one person out of ten will develop active symptomatic TB. The other nine persons have a functional immunological system which maintains the infection quiet and sleeping ('latent TB').

When the immune system becomes weak due to HIV, the sleeping infection may take advantage of this to turn active and cause the disease of TB.

The usual probability (or risk) of a person of getting sick from TB after TB infection is not high (10%), but in the person infected with HIV, the probability to develop TB is much higher, due to the weak immune system.
A person infected with HIV has a 50% probability of developing TB disease!

Important to know is that in HIV, more than half of the patients with pulmonary TB will not have a positive sputum test!
A negative sputum result for TB in an HIV positive patient does not exclude TB, but requires further investigation such as chest X-ray in case of persistent symptoms.
Extra-pulmonary TB is more common in HIV positive patients than in HIV negative patients. Extra-pulmonary TB can present with only symptoms of weight loss and fever. That's why we always need to consider TB in HIV+ patients with fever and/or weight loss, even in the absence of other symptoms.
Let's meet some patients. We will follow them through the course.

Maria is a 22-year-old woman. She is HIV+. She thinks she got HIV when having sex with a teacher when she was in school. The teacher died 3 years later, and he was very thin.

Her husband left her when she disclosed her HIV status. Now she lives alone.

She has repeated middle ear infections, and lost some weight, but not a lot. She has no other clinical signs. In what clinical stage is Maria?______

Kato is a 27-year-old man. Before, he was selling some small household material in the street, but now he is so sick he cannot work anymore. He is very weak and has to stay in bed most of the time. He is really very thin and has fever all the time, for several months. He was worried about having AIDS for a long time, but never got the courage to do a test. Now, he heard about free ART, and finally did the test, which is positive.

In what clinical stage is Kato?______

Mr. Richard is a businessman. He is 40 years old. He has a nice house and an expensive car, and lives in Masaka. He is a widower. His wife died 2 years ago. He has 2 young children of 4 and 6 years old, who are in good health. He has a new wife, a younger lady.

Now, his weight has dropped from 75 kg to 73 kg, and he starts to have an itching rash on his arms and legs.

What could you suggest to Mr. Richard?
The nurse counsels Mr. Richard to do an HIV test. The test came back positive.
The nurse advises Mr. Richard to talk about this with his new partner, and use a condom with her. The nurse asked questions about how the first wife died, and talks about the possibility of doing a test for the children and his new wife, though they are healthy.

In what clinical stage is Mr. Richard?_______
Chapter 3: HIV and antiretroviral drugs

Learning objectives

By the end of this chapter you should be able to:

- describe how HIV replicates itself;
- name the different classes of antiretroviral drugs (optional);
- indicate the classes to which different antiretroviral drugs belong (optional);
- explain basics about how the different classes work;
- explain why we need to use a combination of 3 antiretroviral drugs;
- explain the difference between a first-line regimen and second-line regimen;
- describe the benefits of ART;
- describe the goals of ART.
INTRODUCTION

The human body is made out of millions of different cells. Each body cell often makes new cell parts, in order to stay alive and to reproduce. Viruses hide their own material in the inside of the body cell, and then, when the body cell tries to make new parts, it accidentally makes new viruses as well. HIV mostly enters cells in the immune system.

INFECTION OF A CELL

Although HIV infects a variety of cells, its main target is the T4-lymphocyte (CD4), a kind of white blood cell that is responsible for warning your immune system that there are invaders (diseases) in the body.

MAKING NEW COPIES OF HIV

Once HIV binds to a cell, it hides HIV material inside the cell: this turns the cell into a sort of HIV factory.

= HIV
= HIV that has changed
= gate of entry for HIV in the CD4 cell
= part of new HIV
= centre (or nucleus) of the CD4 cell

HIV is entering the CD4 cell.

Now, HIV wants to enter the centre of the cell. To do this, it needs to make some important changes in the way it looks, in order not to be 'recognized' by the cell. HIV has a special substance to make these changes in its structure.
HIV is present in the centre of the cell, in a different shape. Now, the centre of the cell starts to make new parts of HIV instead of making new parts for the body's defence.

Before leaving the cell, the new parts of HIV need to be put together, just like parts of a car need to be put together in the factory before they can leave the factory to be sold. HIV has a special substance that helps to put the different parts together to form a new HIV before it leaves the cell.

HIV attacks many CD4 cells. The infected CD4 cell will first produce many new copies of the virus, and then die. The new copies of HIV will then attack again other CD4 cells, which will also produce new copies of HIV and then die. This goes on and on: more and more CD4 cells are destroyed, and more and more new copies of HIV are made.

ANTIRETROVIRAL DRUGS

HIV is a retrovirus. So drugs against HIV are called anti-retroviral drugs: Anti Retro Viral drugs - shortened to ARV drugs.

Giving ARV drugs in the correct way, with adherence support, is called ARV Therapy - shortened to ART.
HOW DO ANTIRETROVIRAL DRUGS INTERFERE WITH THE LIFECYCLE?

There are 3 big groups of antiretroviral drugs available:
- the NRTI: this stands for 'Nucleoside and Nucleotide Reverse Transcriptase Inhibitors' (divided into NsRTI and NtRTI)
- the NNRTI: this stands for 'Non-Nucleoside Reverse Transcriptase Inhibitors’
- the PI: stands for Protease Inhibitors

The nucleoside and non-nucleoside inhibitors (NRTI and NNRTI) both have the same "target". They prevent HIV from entering the infected cell’s centre, so HIV can't start making new copies.

Protease inhibitors (PI): when the central part of the body cell makes parts of the HIV virus after infection, these parts have to be cut and put together in the right way before the new HIV copies can leave the cell. Protease inhibitors prevent this “cut and putting together” from happening correctly, so the newly produced virus parts cannot leave the infected cell and infect other cells.

The important point is that protease inhibitors and nucleoside/non-nucleoside inhibitors work at different steps in the process that HIV goes through when it makes new copies of itself inside cells.
This page is optional. You will not be tested on it.

THE DIFFERENT ANTIRETROVIRAL DRUGS

The table below mentions commonly used ARV drugs. The table is not complete, and does not contain rarely used drugs, or drugs that are not yet available in most resource-constrained settings. In this course, you only need to be familiar with zidovudine (ZDV or AZT), stavudine (d4T), lamivudine (3TC), nevirapine (NVP), and efavirenz (EFV). These are the ARV drugs used in the first-line regimens.

Table 2

Commonly used antiretroviral drugs

Note that this table and the information on class of drugs in italics on the next pages are optional for this course (you will not be tested on them).

<table>
<thead>
<tr>
<th>NRTI</th>
<th>Nucleoside reverse transcriptase inhibitors (NsRTI)</th>
<th>Nucleotide reverse transcriptase inhibitor (NtRTI)</th>
<th>Non-nucleoside reverse transcriptase inhibitors (NNRTI)</th>
<th>Protease Inhibitors (PI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>stavudine (d4T)</td>
<td>tenofovir disoproxil fumarate (TDF)</td>
<td>nevirapine (NVP) efavirenz (EFV)</td>
<td>saquinavir (SQV)</td>
</tr>
<tr>
<td></td>
<td>lamivudine (3TC)</td>
<td></td>
<td></td>
<td>ritonavir (RTV), as</td>
</tr>
<tr>
<td></td>
<td>zidovudine (ZDV)</td>
<td></td>
<td></td>
<td>booster *</td>
</tr>
<tr>
<td></td>
<td>didanosine (ddl)</td>
<td></td>
<td></td>
<td>indinavir (IDV)</td>
</tr>
<tr>
<td></td>
<td>abacavir (ABC)</td>
<td></td>
<td></td>
<td>nelfinavir (NFV)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>lopinavir (LPV)</td>
</tr>
</tbody>
</table>

* ritonavir is used as a ‘helper’ for another PI in adults, to make the effect of the other PI stronger.
WHY DO WE HAVE TO USE THE COMBINATION OF 3 ANTIRETROVIRAL DRUGS?

Combination therapy makes sense for lots of reasons. Here are the most important ones:

- **It takes a lot of force to stop HIV.** HIV makes new copies of itself very rapidly. Every day, many new copies of HIV are made. Every day, many infected cells die. One drug, by itself, can slow down this fast rate of infection of cells. Two drugs can slow it down more, and three drugs together have a very powerful effect.

- **Antiretroviral drugs from different drug groups attack the virus in different ways.** In the beginning of this chapter, we learned how different anti-HIV drugs attack HIV at different steps of the process of making copies of itself (first when entering the cell centre, and then when new copies want to leave the cell). Hitting two targets increases the chance of stopping HIV and protecting new cells from infection.

- **Combinations of anti-HIV drugs may overcome or delay resistance.** Resistance is the ability of HIV to change its structure in ways that make drugs less effective. HIV has to make only a single, small change to resist the effects of some drugs. For other drugs, HIV has to make several changes. When one drug is given by itself, sooner or later HIV makes the necessary changes to resist that drug. But if two drugs are given together, it takes longer for HIV to make the changes necessary for resistance. When three drugs are given together, it takes even longer.

EXERCISE 3-1

Imagine that you have a patient in your consultation that comes to you and tells you he is taking 2 antiretroviral drugs he received form a family member abroad. What would you say to this patient? Think about this. We will discuss it in small groups during the course.

Notes:

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

The powerful combination of 3 different antiretroviral drugs is called HAART: Highly Active Anti Retroviral Therapy. This is the standard of good therapy, and has the greatest benefits for the longest time.

In this course, whenever we say ART, we mean HAART!
A first-line regimen is a combination of drugs that will be used in a patient who has no prior ART experience. This means that the patient never took ARV drugs before. Most commonly, a first-line regimen will consist of two NsRTI's and one NNRTI.

There are 4 main first-line regimens. These 4 good first-line combinations are:

- d4T- 3TC - NVP
- d4T- 3TC- EFV
- ZDV- 3TC- NVP
- ZDV- 3TC- EFV

Note that 3TC is included in all 4 regimens (always listed in the middle). The first drug is d4T or ZDV (not both together). The last drug is NVP or EFV (not both together). ZDV is the same as AZT.

There are always 3 drugs.

Many patients will eventually develop failure of therapy: the first-line therapy will not be effective anymore (often because the drugs were not taken correctly). In that case, the doctor may decide to switch to a second-line regimen. Usually, the second-line regimen will consist of 2 NRTI + 1 PI. The second-line regimen is stronger, but there are more pills to take, and this regimen has sometimes food restrictions, and sometimes more side effects. Even second-line regimen can fail, if not taken well.

Note: In some countries in West Africa, another type of HIV is existing. This type is resistant to the group of NNRTI's, even if the patient has never taken ART. These countries will have an adapted protocol for first- and second-line regimens.
EXERCISE 3-2

1. Write the abbreviations and the generic names of each of the drugs used in the first-line regimens in your country:

_______________________________________________________________
_______________________________________________________________
_______________________________________________________________

2. Circle the one that is included in all 4 first-line regimens. Now read them out loud.
   d4T________________________________________________________
   ZDV _______________________________________________________
   3TC _______________________________________________________
   NVP _______________________________________________________
   EFV _______________________________________________________

3. What are the two abbreviations for zidovudine? _____  _____

EXERCISE 3-3  Recognize locally available drugs.

List the common brand names of the following drugs and fixed-dose combinations which are used in your area:

   d4T-3TC-NVP ______________________________
   ZDV-3TC ______________________________
   d4T ______________________________
   3TC ______________________________
   NVP ______________________________
   ZDV ______________________________
   ZDV-3TC-NVP ______________________________
BENEFITS OF ART

- Prolongs life and improves quality of life
- Households can stay intact
- Decreased number of orphans
- Reduces mother-to-child transmission
- Increased number of people who accept HIV testing and counselling
- Increased awareness in the community, since more people do the test
- Decreased stigma surrounding HIV infection since treatment is now available
- Increased motivation of health workers, since they feel they can do more for HIV patients
- Less spent to treat opportunistic infections and provide palliative care
- Businesses can stay intact.

WHAT IS THE GOAL OF ART?

- ART blocks viral replication, thus preventing further disease progression and immune system damage.
- The body's defence (immune system) gets a chance to recover and less opportunistic infections occur.

However, antiretroviral therapy does not cure HIV infection.

The goal of the therapy: reducing the number of virus in the blood as much as possible and increase the number of CD4 as much as possible.

The virus can never be eradicated completely, so the person should take the drugs forever, even if symptoms have disappeared.

Since the virus cannot be eradicated, safe sex has to be practised.
Figure showing impact of ART on CD4 and viral load

CD4

No ARV

Shortly after start ARV

After several months of ART

= HIV

= CD4
EXERCISE 3-4

1. How many different drugs do we need to take in order to have an effective regimen?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

2. Is d4T-3TC-NVP used as a first-line or as a second-line regimen?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

3. What are the 2 main goals of ART?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

4. What is a second-line regimen?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

5. What happens if we do not take the combination of several antiretroviral drugs?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
Chapter 4: Adherence and resistance

Learning objectives

By the end of this chapter you should be able to:

- describe what adherence means;
- describe what resistance means;
- explain the link between adherence and resistance;
- explain the consequences of resistance;
- explain what failure of therapy means;
- know the maximum number of pills a patient can forget per month for the regimen d4T-3TC-NVP in a fixed drug combination;
- be able to use an effective local description to explain the danger of resistance in your community.
WHAT HAPPENS AFTER WE TAKE A DRUG BY MOUTH?

When we take a drug by mouth, it first enters the gastro-intestinal tract (stomach, intestines …). In the gastro-intestinal tract, the drugs are dissolved and absorbed through the gut wall into the blood. The drug then passes through the liver. It is then distributed to the tissue, and in the end it is excreted from the body.

When the drugs come into the circulation (the blood) they need to reach a level (or concentration) that is high enough in order to be effective against the virus.

We normally have good drug levels in the blood if:

- We take the correct number of pills as the health care worker prescribes.
- We do not miss a dose or take a dose too late.
- We take into consideration interactions with other drugs which can lower the concentration.

Imagine our body as a bottle with a small hole in the bottom. Let’s now imagine we want to keep the bottle full.

To keep the bottle full, we need to add in time what has been lost through the small hole. If we are late to fill the bottle, the water level drops and the bottle will be half-empty instead of full.

The same is true for drugs in the body: if we do not take our drugs in time, the body will be ‘half-empty’ with drugs. When the body is ‘half-empty’ with drugs, the effect against the virus will not be good.

The HIV virus can defend itself against a low level of drugs, but not against a high level of drugs. This is why we need to make sure that there is always a high level of drugs, by taking our pills correctly.

ADHERENCE

As mentioned above, it is really important to take the drugs correctly in order to be effective.
We say the patient must be adherent to the therapy.

Adherence means accepting, agreeing and following correctly a prescribed treatment (participation of the patient).
HIV is constantly making copies of itself. While making so many copies of itself, it sometimes makes mistakes.

To understand this, think of a box of nails you buy in a shop. When you carefully look at the nails, you will notice that some of the nails look a little different from the other nails.

This was a small mistake during the manufacturing process of the nails.

The same is true for HIV: by mistake, HIV makes some copies that do not look exactly the same as the original. These variations are called mutations.

Some of the HIV variations or mutations can have a special 'coat' around their body, that makes the virus better protected better against the effect of drugs than the original virus. This virus with mutations is a resistant virus. Resistance is a change in the virus that makes the virus protected and ARV drugs ineffective.

When we take the drugs correctly, the virus can not make new copies of itself. Both the 'normal' virus and the mutation are suppressed, because the combination of 3 drugs that are constantly present in a sufficient level in the blood is so strong.

When we do not take the drugs correctly, the level of drugs in the blood is still high enough to combat the normal type of virus. So the number of normal virus will not increase.

Some of the mutations of HIV, however, have the 'protective coat' around them. The protective coat is not strong enough if the level of drugs is high. But when the level of drugs is low, because the patient is not taking the drugs correctly, the coat will protect the virus against the action of the drugs.

This means that the virus with the protective coat (resistant virus) can still continue to make copies of itself, while the normal type of virus can not.

After some time, the body will contain more and more resistant virus, and less and less normal virus.

The result will be that the drugs will lose their effect.

This means that slowly, the number of CD4 will decrease again, and after several months, the patient will start to have new opportunistic infections again.

This is what we call treatment failure.

Key message:
When a patient is not adherent, the patient will develop treatment failure and become sick again.
Example: your patient takes the fixed drug combination of d4T-3TC-NVP, one pill in the morning and one in the evening. If this patient forgets more than 3 pills per month, resistance will develop!! This needs to be explained to the patient.
Patients need to know that if they do not take the ARV drugs with very high adherence, the drugs stop working - both for the individual and gradually for the whole community (because of resistance). First-line treatment is the most effective and easiest to take (less side effects than second-line treatment). First-line treatment can give years of life if the patient has almost perfect adherent. Second-line treatment is harder to take and more expensive.

**EXERCISE 4-1**

What is a good way to explain the problem with ARV resistance to the people in your community, so they will understand the importance of near perfect adherence both for themselves and for their community?

Use local language and comparisons (how would you really explain it, what examples would you use).

We will discuss this in small groups in the course.

**Notes:**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Chapter 5: Assess (clinical review of symptoms and signs, medication use, side effects, complications) and provide clinical care

Learning objectives

By the end of this chapter you should be able to:

- describe why doing the complete assessment is crucial in HIV/AIDS patients;
- do the complete assessment (this includes the clinical review in Step 3 of Chronic HIV Care with ARV Therapy; Step 4: assess family including pregnancy, family planning, and the HIV status of partners and children; and Step 5: review TB status;
- know where to refer to in the appropriate parts of the Acute Care module where indicated in the assessment;
- understand the meaning of the clinical signs and symptoms in HIV patients not yet on ART;
- determine what clinical care the patient needs, based on the assessment in Steps 3, 4 and 5.

Your patients have returned. Read this chapter to learn how to assess and provide care for these patients. (Answer questions at the end of the chapter.)

Maria comes to the consultation with blisters on one side of the chest. It is really painful. It started 2 days ago. In the meantime, Maria has met a new man, with whom she would like to have children in the future, but not now. She is using oral contraception.
Kato is being assessed by the nurse in the health centre. He complains again about his severe weight loss, and about the chronic fever. He is also coughing from time to time for the last 3 weeks. The medical assistant sent 3 sputums last week. He has an itching rash on arms and legs, and some small wounds at the corners of his mouth. He tells the nurse he is desperate to get ART, if possible today, if not he will die, he says.

Mr. Richard has lost even more weight. His healthy weight was 75 kg, and now it is only 66 kg. He has no other signs or symptoms, except for the itching rash on arms and legs. He is not coughing. He still keeps on working. He has gone to Kampala to do a CD4 test. The result was 150 cells/mm³.

For any HIV+ patient, always use the clinical review on page Section 3.1 and 3.2 of the Chronic HIV Care Module. (Keep a laminated copy of it in the clinic.) If this review shows that there are new signs or symptoms, you will in addition need to do further assessment of these signs or symptoms and decide what the problem is and how to treat it. This further assessment is in the Acute Care module (or your national guidelines on acute care for adults). The possible explanations for the same signs and symptoms increase when the immunity of the HIV patient declines. There are more possible explanations when ART is added- this is summarized in the table below.
Possible causes for signs and symptoms

<table>
<thead>
<tr>
<th>HIV negative patient</th>
<th>HIV positive patient -- No ART</th>
<th>HIV positive patient -- On ART</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Opportunistic infections</td>
<td>Immune reconstitution syndrome</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ART side effects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Opportunistic infections</td>
</tr>
<tr>
<td></td>
<td></td>
<td>From failure of therapy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (for example, CD4 still</td>
</tr>
<tr>
<td></td>
<td></td>
<td>not high enough to protect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>the patient)</td>
</tr>
<tr>
<td>Common infections and</td>
<td>Common infections and other</td>
<td>Common infections and other</td>
</tr>
<tr>
<td>other acute and chronic</td>
<td>acute and chronic problems</td>
<td>acute and chronic problems</td>
</tr>
<tr>
<td>problems (not related</td>
<td>(not related to HIV)</td>
<td>(not related to HIV)</td>
</tr>
<tr>
<td>to HIV)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

We will discuss immune reconstitution syndrome and the side effects of ART in Chapter 9. Right now our aim is to learn to do the clinical review and to understand what the signs and symptoms may mean in an HIV patient before they start on ART. This will help us provide good chronic care and to learn to determine when ART is needed.

The same clinical review can later be used in patients on ART. The interpretation of signs and symptoms then includes side effects and other possibilities that are explained in Chapter 9. We will learn this later.

In doing the clinical review, it is important that we review signs and symptoms that are included in the clinical review on section 3.1 and 3.2 of the Chronic HIV Care Module. We must also address the patients concerns and priorities for this visit. This is an important part of good chronic care:

A general principle of good chronic care:

6. Focus on your patient's concerns and priorities
Assess: Clinical review of symptoms and signs, medication use, side effects, and complications (look at section 3.1 and 3.2)

3.1 ASK

- If this is the first visit, review the patient's history. Check record for TB, other opportunistic infections, chronic problems.

Reviewing the history is necessary to determine the WHO clinical stage. The clinical stage will determine whether ART can be considered for this patient, and will determine the need for prophylaxis.

An example: your patient presents with Herpes zoster and no other symptoms. If you do not take the history, you would categorize the patient in WHO clinical stage 2. But, imagine this patient had pulmonary TB last year. This would mean that the patient is not in stage 2 but in stage 3. (It is always the worst sign, symptom or disease that determines the stage. The patient can go up in clinical stage classification but not down. That does not mean the patient will not improve clinically- they will but technically they still are classified with the worst stage that they ever reached.) So, in this case, not asking about the history will underestimate the stage of HIV/AIDS disease. Underestimating disease can mean your patient does not get access to ART when s/he needs to.

For all visits, ask:

- How have you been?

Give the patient the opportunity to mention anything special, or anything that is important for him, before starting specific questions. This is a valid source of information, and will help you get a general idea of how the patient feels (both physically and mentally), or of how important a certain problem is for the patient.

- Have you developed any new symptoms or problems?

It is important to ask this open question, so that the patient can mention any problem, since not all possible health problems are mentioned in the list of specific questions below.

- Have you had any of the following? If yes, ask for how long and go to the Acute Care guidelines.

It is necessary to go through this list, because it is a summary of the most important and frequent symptoms that can occur in HIV/AIDS patients.
**Cough?**

*Cough can be a symptom in many opportunistic infections:* pulmonary TB, or bacterial pneumonia or *Pneumocystis carinii* pneumonia and many others.

Using the *Acute Care* guidelines pages 16 to 17 will help you determine which exams or treatment is needed for the cough.

**Night sweats?**

Night sweats can be the beginning of an opportunistic infection. Night sweats can be a sign of TB or pneumonia.

**Fever?**

- Fever can be due to an opportunistic infection or another infection such as malaria or other conditions including drug reactions.

Assess further using the *Acute Care* guidelines (pages 24 to 25), to look for apparent causes of fever, and when necessary call for advice or refer. (If the patient is on ART, considerations are discussed in Chapter 9.)

**STI signs?**

Asking about STI in all patients is useful, because many patients feel uncomfortable about it, and thus will not mention it spontaneously. Asking about STI can help you suspect unprotected sex; this can be an opportunity to reinforce information and education about safe sex, without judging the patient. It can help you to determine the clinical stage (in case of chronic Herpes simplex). Most importantly, it will help you to treat your patient and his/her partner(s) as early as possible for the STI. Prompt treatment of STI is important for reducing transmission of HIV.

*Herpes simplex* is an STI that can recur from time to time, even if the patient had no unprotected sexual contacts. It does not mean that the HIV disease is progressing. If the lesions are very extensive and do not heal after a full month, this places the patient in WHO clinical stage 4.

Look at Photo N

Look at Photo O

*Genital warts* can also relapse from time to time after treatment, even if safe sex is being practiced.

Look at Photo P

Look at Photo Q

*Other STI* that appear for the first time should make you suspect that the patient had unprotected sex. Discuss and reinforce education. Treat according to the *Acute Care* guidelines. Treat partner(s) as well.
Diarrhoea?

Diarrhoea can be acute diarrhoea, as in HIV negative patients. It needs the same initial management. (See Acute Care pages 28 to 30 and the fluid treatment plans on pages 88 to 91.)

Persistent diarrhoea is a sign of clinical stage 3. It needs special management. This is explained on section 9.1 of the Chronic HIV Care Module.

Mouth sores?

Look at Photo F

New skin rash?

Look at Photo R

Certain OI can present with a skin eruption. Certain skin rashes indicate that the patient is stage 2 (see Chapter 2).

New skin rash in a patient on ART can be very serious - see Chapter 11 and section 8.12 of the Chronic HIV Care Module.

Headache?

Asking for headache is crucial in all HIV/AIDS patients. Headache can be the manifestation of life-threatening meningitis. Certain types of meningitis are common in HIV/AIDS patients, and they can present without neck stiffness.

Fatigue?

Fatigue is a common problem in HIV patients with immunosuppression and OIs. It can also be a sign of anaemia or of lactic acidosis.

Nausea or vomiting?

Poor appetite?

Poor appetite is common in HIV/AIDS patients. Giving education about nutrition is important to prevent further weight loss. In most cases, appetite increases gradually when patients get better on ART.

See the advice on P23 of the Palliative Care module. This module has a lot of both home care and medical advice on managing bothersome symptoms.

Tingling, numb or painful feet or legs?

This can also be described as burning. This is called peripheral neuropathy. If the patient is not yet taking ART, this can be due to certain OIs, or due to HIV itself, or to TB drugs. Peripheral neuropathy can also be a side effect of certain ARV drugs (see Chapter 11)
Any other pain? If yes, where?

Go to the *Acute Care* module where needed to determine and treat the cause.

Use the *Palliative Care* module for pain management. Pain management is very important for patient well-being.

**Sexual problems?**

Patients having a sexually transmitted disease as serious as HIV/AIDS can suffer from feelings such as anger towards the people who might have contaminated them, or guilt because they might have contaminated their partner, or fear to contaminate their partner, and many other feelings. All this can affect the sexual life of the patient.

When patients have sexual problems, they are not only unhappy but it may make it less likely that they use condoms.

- **Have you needed urgent medical care? If yes, ask for record/diagnosis**

Knowing any important medical events may help you determine whether a patient had side effects or OI. This can help you adapt/determine the clinical stage, or knowing drugs that the patient does not tolerate.

- **Which medications are you taking and how often?**
  - Reviewing all drugs the patient takes is a good way of checking whether everything is understood well, and that both patient and health care worker are aware of the drugs that are taken.
  - This gives information about other medication that you might not know about. (For example because the patient went to a private practitioner.)
  - It will help you to check whether there are drugs that are not compatible (due to antagonism, interactions or similar toxicity (see section 10.2 of the Chronic HIV Care Module).

- **Assess adherence** *(section 8.9 "Monitor and support adherence" Chronic HIV Care Module)*

Assess adherence to cotrimoxazole prophylaxis (or later, ART) as part of the clinical review. This is very important and is covered in a later chapter 12. Do not start counselling now. You need to first finish the clinical review.

- **What problems have you had taking the medicine?**

The response to this question will help you to address any difficulties the patient had, reinforce education, provide more tips and tools on how to take the drugs correctly or in rare case consult with the doctor about the need to change the regimen.

- **Taken any other drugs?**

- **How are things at home?**

The situation at home can reinforce adherence, or can be a barrier to adherence. For example, if the patient needs to hide the status for other family members, he might forget the drugs more easily, because there is nobody to remind him, or because he needs to be alone to take the drugs.
• **What usual physical activities are you doing?**

Asking whether the patient is able to go to work or school, or whether he needs to stay in the bed all the time gives a good idea of the general condition of the patient. Treating OI and giving ART will in most cases bring a gradual improvement in the functional status of the patient.

The information on usual physical activities will allow you to determine the functional status (see section 3.5 of the *Chronic HIV Care Module*). Classify the patient as either able to work, go to school, do housework, or harvest (WORK); ambulatory but not able to work (AMB); or bedridden (BED).

The more the patient has deteriorated by the time therapy is initiated, the longer it can take to get full recovery of physical capacity. Some patients might not be able to have a full recovery of physical activity, despite correct treatment with ART.

• **Is there anything else you want to talk about?**

It is a well known phenomenon that problems that make the patient feel uncomfortable or ashamed are not said in the beginning of the consultation, even when you ask for it. Often the patient needs to gain some courage, before he dares to share something difficult but important with the health care worker. That is why important things are often only mentioned at the very last moment, and asking this question is a way to help the patient to come up with some difficult topic.

### 3.2. **LOOK**

• **Look for pallor**

Look at Photo S

Look at Photo T

Pallor can be caused by anaemia. This can be due to certain **opportunistic infections** (like disseminated TB). HIV infection itself can also give anaemia of chronic disease. Check haemoglobin and call for advice if lower than 8g/dl.

• **Look at white of the eyes: yellow?**

Look at Photo U

Yellowing of the white of the eyes can have different causes. An important cause is a sick liver.

The liver can be sick due to **certain drugs**. A sick liver can also be caused by some virus, for example hepatitis A or B virus.

• **Look for thrush**

Look at Photo V

Look at Photo W

Looking for oral thrush is a quick and easy way to see any disease progression. Patients with oral thrush are in WHO clinical stage 3.
• **Weight**

The weight of a patient is an important way to monitor clinical status and gives a first impression of the response to therapy. Patients should be accurately weighed with a beam or balance scale on each visit (there is a column for recording this on the HIV Care/ART card). Patients should gain weight gradually when they are on ART.

Weight loss is one of the signs for clinical staging. This requires calculating the percent weight loss.

This can be done with a calculator or by hand using the formula:

\[
\% \text{ weight loss} = \frac{\text{old weight} - \text{new weight}}{\text{old weight}}
\]

• **Count pills to estimate adherence**

See Chapter 12.

• **If patient is sad or has lost interest, assess for depression**

Depression can be a major accompanying condition in patients with AIDS, but depression symptoms can be confused with other symptoms that often accompany AIDS, such as, loss of appetite or lethargy or other symptoms. In addition, depression can be a major barrier for adherence to therapy.

Ask the patient if they are feeling sad or depressed. Of course, while the patient may deny or not be aware that he or she feels sad or depressed, the depression may be reflected in lack of interest, energy, or neglect of oneself. Asking the question does no harm and will not make the patient more depressed. Counselling and medication can relieve depression in patients with AIDS even in cases of advanced illness.

• **If any new symptoms:**
  - Measure temperature
  - Check for nodes
  - Look for rash
  - Look for evidence of violence
  - Do further assessment

• **If first visit (and every 6 months for follow up visits), check the patient’s memory:**

First explain to the patient you want to check his memory to avoid the patient getting confused by the rather unusual questions that follow.

Name 3 unrelated objects (of course in the local language), clearly and slowly.

For example, tell the patient: "I would like to do a small test to check your memory. I will name 3 objects. Listen carefully while I speak: FLOWER, PEN, HOUSE." I will ask you to repeat them shortly and then after a little while.

Now ask the patient to repeat the three words you just said.
If the patient cannot repeat the 3 words, it is probable that the patient has not registered them well in the brain. This is a problem in **registration**. This is sometimes due to serious problems in concentration or in understanding, but can be due to HIV effects on the brain or other infections or problems. What has not registered cannot be reproduced (said back), even not immediately after the 3 words were spoken.

Problems in **registration** are more serious than problems in **recall**.

After 5 minutes (you can fill out the patient card or do something else in the mean time), ask the patient to again repeat the 3 names. If he cannot say the 3 names, there may be a **recall** problem.

Memory problems can be caused by many things: it can occur in advanced AIDS, often together with other neurological deficits, or by chronic excessive use of alcohol, other drugs and some medications.

It is important to consider the cause of the memory problem; this may require referral. It is also important to take the memory problem into account when you prescribe medications. It is not likely the patient can remember the number of pills he needs to take if he has a memory problem. A treatment supporter needs to come with the patient, or other measures need to be taken to ensure adherence to the medication and other elements of the treatment regimen.

### 3.3 Lab

When possible, obtain a CD4 count to help decide when the patient is medically eligible for ART and to provide a baseline. Then repeat the CD4 count to monitor response every 6 months or when treatment failure is suspected. (We will discuss this in Chapter 15.)

Lack of a CD4 count should not delay initiating ART when the patient has clinical criteria for medical eligibility. **Absence of lab should not delay ART.**

When possible, obtain haemoglobin and an RPR (if an RPR has not been done within the last year). Again, **absence of lab should not delay ART.** However, it is essential to have a haemoglobin result before starting ZDV. It is desirable for all patients to have a baseline haemoglobin determination.

When patients return for follow-up, make sure you check for lab results from the previous visit.
### 3.4 Determine clinical stage - use pages 26-27 for adults and adolescents

The clinical stage determines when to give prophylaxis and when to give ARV therapy:

<table>
<thead>
<tr>
<th>WHO Clinical Stage 1 Asymptomatic</th>
<th>WHO Clinical Stage 2 Mild Disease</th>
<th>WHO Clinical Stage 3 Moderate Disease</th>
<th>WHO Clinical Stage 4 Severe Disease (AIDS)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Prophylaxis (according to national policy)</strong></td>
<td><strong>Prophylaxis (according to national policy)</strong></td>
<td><strong>Prophylaxis (according to national policy)</strong></td>
<td><strong>Prophylaxis (according to national policy)</strong></td>
</tr>
<tr>
<td>☐ INH prophylaxis if eligible</td>
<td>☐ INH prophylaxis if eligible</td>
<td>☐ INH prophylaxis if eligible and able to exclude TB&lt;br&gt;☑ cotrimoxazole prophylaxis</td>
<td>☐ INH prophylaxis if eligible and able to exclude TB&lt;br&gt;☑ cotrimoxazole prophylaxis&lt;br&gt;☑ Other prophylaxis on Treatment Plan</td>
</tr>
<tr>
<td>☐ Cotrimoxazole prophylaxis</td>
<td></td>
<td>☐ If CD4 not available, treat all in stage 3&lt;br&gt;☑ If CD4 available, take into consideration CD4 &lt; 350 when deciding when to treat&lt;br&gt;☑ See section 8.1: Evaluate for ART&lt;br&gt;☑ Prepare for adherence</td>
<td>☐ All in stage 4 are medically eligible&lt;br&gt;☑ Evaluate for ART (section 8.1)&lt;br&gt;☑ Prepare for adherence (this requires several visits and home visit if possible)</td>
</tr>
<tr>
<td><strong>ARV therapy</strong></td>
<td><strong>ARV therapy</strong></td>
<td><strong>ARV therapy</strong></td>
<td><strong>ARV therapy</strong></td>
</tr>
<tr>
<td>☐ Only if CD4&lt;200</td>
<td>☐ Only if CD4&lt;200 or Total lymphocyte &lt;1200/mm3</td>
<td>☐ If CD4 not available, treat all in stage 3&lt;br&gt;☑ If CD4 available, take into consideration CD4 &lt; 350 when deciding when to treat&lt;br&gt;☑ See section 8.1: Evaluate for ART&lt;br&gt;☑ Prepare for adherence</td>
<td></td>
</tr>
</tbody>
</table>

Note that the number of the clinical stage of a patient can only go up (for example from 3 to 4) and not go down (for example from 3 to 2).

An example: your patient has oral thrush. Oral thrush means the patient is in stage 3. You prescribe treatment for oral thrush, and cotrimoxazole prophylaxis. Some weeks after the treatment, the patient comes back to the consultation to receive a new prescription for cotrimoxazole prophylaxis. He has no symptoms, and the candida has resolved. The fact that the patient has no symptoms on this consultation does NOT mean he has returned to the asymptomatic stage 1. He remains in stage 3, even if he has no symptoms now, since his state of immunity corresponds with stage 3.

The rows at the bottom of the clinical staging chart indicate when to offer cotrimoxazole prophylaxis and when patients are medically eligible for ART.
3.5 Determine functional status

You already have the information from the question in the clinical review “What usual physical activities are you doing?” If you do not already have enough information to decide which functional status the patient is in, ask some more questions and then record on the HIV Care/ART Card. Put the patient in the most functional status s/he achieves.

The first category WORK assumes that the patient is also ambulatory. If the patient is ambulatory but not strong enough to work, then record as AMB.

Functional status is a good indication of improving or worsening clinical status, as is weight.

<table>
<thead>
<tr>
<th></th>
<th>Record on the HIV Care/ART card:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to work, go to school, do housework, or harvest</td>
<td>WORK</td>
</tr>
<tr>
<td>Ambulatory but not able to work</td>
<td>AMB</td>
</tr>
<tr>
<td>Bedridden</td>
<td>BED</td>
</tr>
</tbody>
</table>

4 Assess family status including pregnancy, family planning, and HIV status of partners and children

In women of childbearing age, it is important to determine pregnancy status.

- Date of last menstruation?
- Using contraception?
- Breastfeeding?

By asking appropriate questions, determine whether she is planning to have a child in the near future. If she is pregnant or is planning to have a child in the near future, it is important to discuss the PMTCT interventions available to her.

Determine if the partner has been tested. Counsel on the advantages of partner testing.

If the woman does have children, ask about whether or not her children have been tested yet and whether her children's HIV status is known.
5 Review TB status in all patients on each visit

The facilitator will demonstrate how to review TB status and you will do some exercises.

The full assessment includes steps 3, 4 and 5. These should be done together before deciding on the clinical plan.

After the assessment steps 3, 4 and 5, you now know a lot about the patient:

- What signs and symptoms they have and whether these are new
- What their clinical stage is and whether it has just gone up (from 1 to 2, for example)
- Any laboratory results including haemoglobin and CD4 count if available
- The patient’s functional status
- The status of pregnancy and contraception use
- TB status

Now you need to use this information to decide what clinical care to provide. The table in section 6 will guide you in choosing what treatments (or referral) that the patient needs. Note that a patient can have signs and symptoms that put them in more than 1 row.

In some cases, you will need to go to 2 other guideline modules to determine the treatments the patient needs: Acute Care and Palliative Care. Practice looking up where to find advice in these two other modules.

The bottom two rows of the clinical staging table in section 3.4 of Chronic HIV Care Module to tell you about eligibility for cotrimoxazole prophylaxis and ART:

Patients in clinical stage 2, 3 or 4 are all eligible for cotrimoxazole. You will learn how to offer cotrimoxazole prophylaxis in the next chapter.

- The patient’s clinical signs and their clinical stage (and CD4 count if available—this is optional) determines whether the patient is medically eligible for ART. This is indicated on the bottom row of the WHO adult clinical staging chart (section 3.4). You will learn more about this in Chapter 8.

Read section 6 then your facilitator will lead you in a drill.

Pages P6 to P7 in the Palliative Care module summarize how to integrate specific management of acute conditions and symptom management.
EXERCISE 5-1

Our three patients are still in clinic, waiting for care. Look back at their stories at the beginning of Chapter 5.

Questions on Maria:
What clinical stage was she on the previous visit (go back to pages 26)? _______
What clinical stage is she on this visit? _______
Maria wants some treatment for her very painful blisters.
What would you give her? _______________________
Where in the guideline modules could you find the treatment she needs to get? ________

What questions and counselling is needed concerning her new partner?

For Kato, the nurse checks the TB sputum register. The sputums the medical assistant sent last week are all negative. She also did a malaria blood smear to try to find an explanation for the fever, but it was negative as well. What should she do?

Mr. Richard asks the nurse for advice on what to do.
What would you advice Mr. Richard?
Where in the module do we find the answer on what to do?
Chapter 6: How to use the HIV Care/ART Card

Learning objectives

By the end of this chapter you should be able to:

- understand how the HIV Care/ART card is used;
- fill out the HIV Care/ART card.

Effective chronic HIV care including ART requires keeping track of what happened on previous visits. Any member of the clinical team who sees the patient needs to be able to know key clinical details and what education and support the patient has been given on the previous visits, in order to know what to do on this visit. In this chapter you will learn to use a treatment card that should stay in the clinic, for use on each patient visit. This card is called the HIV Care/ART card. It is designed to be used from the time that the HIV+ patient registers for chronic HIV care. It is not only for ART.

The patient may also have a health passport or exercise book in which more detailed information on treatment of acute problems can be written. Or your clinic may also keep a chart which includes both the HIV Care/ART card and more pages for acute care visits.

An advantage of the HIV Care/ART Card is that it puts in one place a summary of the patient's chronic HIV care and ART. It helps the clinical team keep track both of the individual patient and all patients receiving chronic HIV care. This will be important as the number of these patients increase.

Someone on your clinical team will also learn to fill out a register and report forms. This is covered in another short training module.

A general principle of good chronic care:

7. Use written information-registers, treatment plan and treatment cards - to document, monitor and remind.

Annex B contains a copy of the complete card. Your facilitator will give you copies of the card to use during exercises.

In this version of the card, there are three different pages:

- The summary (or "face") page, including the address, sex, other family members, the summary of the patient's ART history, etc.
- The encounter page. On this page, for each visit, one row is filled out.
- On the back of this encounter page is a summary of the education and counselling that the patient has received.
When an HIV positive patient decides he or she wants to have ongoing care in your clinic, fill out a card for the new patient. This is called enrolling in chronic HIV care. This does not happen automatically when the patient receives a positive HIV test result. Patients need to understand what is involved in HIV care and want to be cared for on an ongoing basis (with follow-up appointments). This is the first step in forming a partnership with the patient. Some patients will want to think about this for a while or, if they are not yet symptomatic, may want to come back later to enroll in regular care.

The card on the following page illustrates the information filled out on the first visit. On that visit, you will also fill out the first row on the encounter page.

Other information on the card will be added by other health workers and the dispenser at the health facility on subsequent visits. Note that you need to check the written documentation of the HIV test before filling in the results. If only verbal results are given, the patient will need to have another rapid test performed at your facility.

**Numbers on HIV Care/ART Card correspond to the following explanations:** Look at these pages when filling out card.

1. **Write the patient's name, address, sex and marital status.**

2. **Write the HIV Care or ART unique number**
   (according to the system chosen by your national programme). If there is another unique number, write it here.

3. **Write the name of your health unit.**
   For example, Hilltop Health Centre (H.C.).

4. **Write the name of the District Clinician or team assigned to oversee the care for the patient.** Circle to identify which it is. For example, Jessica Elder is assigned to the clinical team which includes Dr Tambo.

5. **Enter the date and location of the HIV test here.**
   Also circle if confirmed and whether it is HIV 1 or HIV 2. If the patient is less than 18 months, circle whether it is an antibody test (the rapid HIV test) or has been done with PCR. See chapter 15 for an explanation of this.

6. **Prior ART**
   It is important to note whether the patient has prior experience with antiretroviral therapy when they first enter into HIV care. Having this knowledge will influence what to do with the patient who comes for the first time i.e. whether to refer as will be discussed in chapter 9.

Under this section, tick whether the patient has prior ART experience such as a transfer in to the health centre with records that indicate the regimen (i.e. the patient has moved into this district with his/her records from another district).

The patient may have been a woman who took ARV drugs for prophylaxis in pregnancy, so PMTCT only may be ticked. If the patient has taken ART before, but is not a transfer in with records i.e. bought ART on his/her own, then earlier ARV, not transfer in should be ticked. Finally, if the patient has no prior ART experience, then tick None.
HIV CARE/ART CARD

Unique #
District
Health unit
District physician/team
Pt clinic no

Name

Sex: M □ F □ Age____ DOB____ Marital status____

Address

Phone (whose)

Prior ART:
- Transfer in with records
- PMTCT only
- Earlier ARV, not transfer in
- None

Care entry point:
- PMTCT
- Medical <5
- TB STI
- Private/Co
- Inpatient
- IDU
- Adult Sex
- Self-refer
- CBO
- Outpatient
- Outreach
- Other:

Treatment supporter/medical pick-up if ill:

Address

Home-based care provided by:

Names of family members also in care

ART treatment interruptions

<table>
<thead>
<tr>
<th>Unique #</th>
<th>Stop</th>
<th>Lost</th>
<th>Date</th>
<th>Why</th>
<th>Date if restart</th>
</tr>
</thead>
</table>

Why STOP codes:
1. Toxicity/side effects
2. Pregnancy
3. Treatment failure
4. Poor adherence
5. Illness, hospitalization
6. Drugs out of stock
7. Patient lacks finances
8. Other patient decision
9. Planned Rx interruption
10. Other__________

Why SUBSTITUTE or SWITCH codes:
1. Toxicity/side effects
2. Pregnancy
3. Risk of pregnancy
4. Due to new TB
5. New drug available
6. Drug out of stock
7. Other reason (specify)

Reasons for SWITCH to 2nd line regimen only:
1. Clinical treatment failure
2. Immunologic failure
3. Virologic failure
7. Care entry point
For the new patient, it is important to know from where in the health care system the patient has come, so for each patient circle one. If the patient was referred into HIV care from PMTCT, then circle PMTCT on the card. If the patient came on his/her own, then circle Self-refer. If the patient was referred into HIV care from the hospital, then circle Inpatient, and so on. The following list is the explanation of each code.

PMTCT  PMTCT/antenatal PMTCT—from antenatal clinic; detected by PMTCT project testing of pregnant women
Med    Outpatient medical
<5     Outpatient—under 5 clinic or paediatric clinic
STI    Outpatient—STI (sexually transmitted infection) clinic
TB     Outpatient—TB
Private Private—private provider
Co     Company/business
Inpt   Inpatient
IDU    Outreach/special services—Injecting drug user
Sex    Outreach/special services—Sex worker
Adol   Outreach/special services—Adolescent
Self   Self—referred (via VCT)
CBO    CBO-referred (via VCT)
Other: Police, military, etc could be written in or added as code.

8. Treatment supporter/med pick-up
Ask: It will be very important to continue your care. If you are sick or for any reason cannot come to the clinic, who could let us know and, if necessary, come to pick up your medication?

What is his or her address? Do you or your treatment supporter have access to a telephone or a mobile phone? If so, what is the number? Record the responses on the card.

Some patients may tell you that the person who will pick up their medications, if needed, is their Treatment Supporter. Or a Treatment Supporter may be listed on their ID card or in the records. The Treatment Supporter is someone who lives with or near the patient, and helps them with their treatment. (During preparations for ARV therapy, a health worker may help the patient choose the Treatment Supporter.)

If the patient has named the treatment supporter as the person who could pick up medications, then circle treatment supporter on the HIV Care/ART Card.

If your patient is lost to follow-up, this information will be very important.

9. Name, age, HIV status and unique patient number (#) for family members also in care.
Family-based care requires keeping track of the whole family-patient, children and partner. In this box, there is room to fit the names/ages of the patient's partner and children and their HIV unique number. This way the whole family can be linked together.
10. **ARV therapy sequential summary box**

The health worker will need to fill out the top part which includes the date for each step or change in the very important sequence: medically eligible; eligible and ready (ready for adherence); **Start ART** first-line; **Substitute** drug - the patient is still on ART first-line; **Switch** to second-line regimen.

Once the patient is medically eligible and ready for ART which means that the patient has been prepared for adherence (minimum of 3 visits), write the date on the line.

If the patient has transferred in from somewhere else but was on ART and you are continuing the ART, it is important to write the date of transfer, from where the patient transferred in and when ART was started.

When first-line ART is started, write the date, the patient's weight and the functional status at the start of ART as well as what the first-line regimen is.

The district clinician will make the decisions on **Substitute** and **Switch** to second-line and code the reason "why" for regimen change. Write in the new regimen and record the Why code.

11. **Stop ART or Lost**

In patient's who have started ART and have stopped ART or are lost to follow-up, circle whether **Stop or Lost**, record the date and the reason code for why stopped. The reason codes are listed on the card.

If ART is restarted, record the date of Restart.

**COMPLETING HIV CARE/ART CARD Encounter Page (Side 1) FOR EACH FOLLOW-UP VISIT**

- Be sure to closely follow the instructions in the bubbles numbered 12-26 on the encounter page on the next page. Record all of the required information on the card.

- Each row on the card is to be used for a separate visit.

12. **Write the date of this encounter with the patient.** If this is a scheduled visit, check the box. Write in the **Date** column to indicate if treatment supporter collected drugs. (In this case the entire row is a non-visit client service, and the name of the treatment supporter or other support person can be entered in the **Side Effects** column, especially if it is different/changed from the person identified in the top left section of the card.)

13. **Record the date for the next follow up appointment.**

Record the date to return for health worker monitoring, re-supply, or any other reason. You should also write the date down for the patient to take with him.

14. **Duration since first starting ART/since starting current regimen**

Put the number of weeks or months. When ART is first started, write "0" in this column.
15. **Record the patient’s weight** in kilograms (kg).

**Before ART is started:** If weight loss compared to prior known weight, also put the % loss with minus (for example, -5%). Remember from chapter 5,

\[
\text{% weight loss} = \frac{\text{old weight} - \text{new weight}}{\text{old weight}}
\]

**When patients are on ART:** Put weight at start of ART on the summary sheet. In patients who have lost weight before starting ART, it is useful to follow weight gain in the first year to see their response to ART. After starting ART, use the weight on the day ART was started to compare the current weight.

\[
\text{% weight gain on ART} = \frac{\text{new weight} - \text{weight when ART started}}{\text{weight when ART started}}
\]

Most patients should gain weight gradually over the first 6-12 months that they are on ART.

16. **For women of childbearing age, ask at each visit:** Are you pregnant now, or do you think you might be? If the patient is pregnant, write "Preg" for pregnancy. Childbearing age is 12 years to 45 years; it is important to ask these women about pregnancy each visit. If pregnant, also write the due date. **For all adolescent or adult patients, ask about family planning at each visit.** Record FP or No FP. If on family planning, record the methods. Ask both men and women about current family planning at each visit.

**For children, use this column to record Height.**

17. **Record the functional status.** Determine which functional status best applies to the patient: Working, Ambulatory, or Bedridden. Refer back to Chapter 5 for the definitions.

18. **Write the clinical stage** (1, 2, 3, or 4). Refer to Chapter 2 for clinical staging.

19. **Check then record the TB status.** Check and record TB status each visit. Remember from chapter 5, the TB status will be one of the following: TB Rx, No signs, Sputums (enter if sent or the results as appropriate), ?TB-refer, or INH. If sputums are sent, also record this in the TB sputum register.

If the patient is on INH, you can use this column to record the number of tablets dispensed and an estimate of adherence.
| Date | Check if scheduled. Write in alternate pick-up if ill. | Follow-up date | Duration since first starting ART/ since starting current regimen? | Wt | Pregnant PMTCT? Due date or FP no FP yes: Methods | Flow | Function | W ork | WHO Clinical Stage | TB Status | Potential SIDE EFFECTS | New OI, Other PROBLEMS | Cotrimoxazole Adhere/Dispense | Other meds dispensed | ARV drugs Adherence Dispense | CD 4 Hgb RPR, TLC, other lab | Refer or consult on link/ provide |
|------|--------------------------------------------------------|----------------|-----------------------------------------------------------------|----|-------------------------------------------------|------|----------|------|-------------------|----------|------------------------|---------------------------|----------------------------|----------------------|-----------------------|--------------------------|
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
|      |                                                        |                |                                                                 |    |                                                                 |     |          |      |                   |          |                        |                           |                           |                      |                       |                          |                        |                      |
20. **Potential side effects**
   Record the possible side effects using the abbreviations in the following list or write out the whole word. "Potential" is used because it is sometimes unclear whether a new sign or symptom is a side effect or another problem.

   **Codes for potential side effects or other problems:**
   N = Nausea  
   D = Diarrhoea  
   F = Fatigue  
   H = Headache  
   BN = burning/numb/tingling of feet or hands (peripheral neuropathy)  
   R = Rash  
   An = Anaemia  
   Ab = Abdominal pain  
   J = Jaundice  
   Fat = Fat changes  
   CNS = dizzy, anxiety, nightmare, depression  
   If other, write in symptoms or signs.

21. **New OI, other problems**
   These can be related to HIV, ART or be problems of unknown cause. Use the abbreviations or write the whole word. You can also use the codes from the list above. (A sign or symptom may be a side effect in one patient or an OI or other problem in someone else.)

   **Codes for new OI or Other Problems**
   (or Write in or use codes to left):
   Z = Zoster  
   P = Pneumonia  
   De = Dementia/Enceph  
   Thrush = oral, vaginal  
   Ulcers = mouth, genital etc.  
   Fever  
   Cough  
   DB = Difficult Breathing  
   IRIS = Immune Reconstitution Inflammatory Syndrome  
   W = Weight loss  
   If other, write in diagnosis or new sign or symptom.

   These code lists are on the back of the summary page. You will learn more about managing side effects in later chapters.

22. **Assess adherence and record dispensing of cotrimoxazole.**
   Later in the course, you will learn how to assess adherence and record it using percentages. Either record the numeric percentage or describe adherence as Good (equal to or greater than 95%), Fair (85-94%), or Poor (less than 85%). Write this in the Adherence column. You will also record reasons for fair or poor adherence using codes from the coding sheet. Record in the Dispense columns the number of pills dispensed that visit.
Codes for Why if poor/fair adherence:
1 Toxicity/side effects
2 Share with others
3 Forgot
4 Felt better
5 Too ill
6 Stigma, disclosure or privacy issues
7 Drug stock out–dispensary
8 Patient lost/ran out of pills
9 Delivery/ travel problems
10 Inability to pay
11 Alcohol
12 Depression
13 Other

23. Record any other medications dispensed. If the patient is taking medicine other than ART, cotrimoxazole, or INH, list the names, doses, and frequency in the Other meds dispensed column.

24. ARV drugs: assess adherence and record ARV drugs dispensed. Later you will learn more about how to assess and record adherence to ART. In this column, you will use the codes from the coding sheet to record adherence and the most important reason for non-adherence in patients with fair or poor adherence. If there is a treatment interruption, (ART is stopped or one patient is lost) record this on the summary page. Write in the dispense column the number of pills given this visit.

25. Document new CD4 count or any other labs. If the patient has had a test to check CD4, Hgb, RPR or any other tests, note what kind of test and when sent, then fill in results when available.

26. Record if any referrals or consults are needed. Note if patient must be referred, or if you need to consult with the clinician. If the patient has been hospitalized, enter the number of hospital days in square brackets.

EXERCISE 6-1

For this exercise, use blank HIV Care/ART cards and fill them in according to the case.

Case Part A:

Patient's name is Mary Sima. Mary is a 35 year-old mother who is married. She comes to the clinic for the first time. She shows you written confirmation of her HIV test which indicates that she has HIV type 2 and was done on January 12, 2004. At that time, the VCT clinic recommended that she come to the health centre but she felt “fine”. She comes today because she has a painful rash on one side of her chest for the last 2 days which has not been helped by the cream she has at home. Mary tells you that she has never been on ART before but thinks she needs it now. Upon further questions, you determine that she lives at the end of Nile Road in the roundabout in Masaka, Uganda. She carries a mobile phone whose number is 078.231.456, and she would like her husband Sam to be her treatment supporter. His mobile number is 078.231.323.
She tells you that she has been married for 5 years and has one 4-year old son whose name is Timothy. Her husband is HIV+ and has been in HIV care for 1 year. At the recommendation of the VCT counsellor, she took her son to get tested in March and found that he was positive as well. She tells you that she was shocked as he has not been sick more than other children. She just made an appointment for him to come into HIV care after she became sick. She and her husband would like to have more children. They use condoms occasionally. Her last menstrual period was over one month ago. She thinks that she could be pregnant, but is not sure. She currently is able to do housework but is not employed.

Mary has had no other medical problems. In fact, she tells you that this is the first time she has a symptom of HIV which is why she comes. Except for the rash her clinical review is negative. Her weight is 54 kg. On physical exam, you see a dark red vesicular (blistering) rash over the right side of her chest extending to her back but does not cross the midline. She has no rash in her eye or the rest of her body.

Her rapid pregnancy test is positive.

Questions:
What clinical stage is Mary?
What treatments or prophylaxis would you recommend?
How would you fill out the HIV Care/ART card for this visit? What missing information do you need to know?

Case Part B:

Mary returns one week later as scheduled and tells you that her rash has improved. You do a clinical review which is negative. Her weight remains the same, and her rash has visibly improved. She tells you that she has been taking the cotrimoxazole everyday and has not missed one dose. You look at her pillbox and agree that she has not missed any doses. You ask her to return before she runs out of the cotrimoxazole. She is still working at home and has gone to PMTCT as was recommended by you at the last visit.

Questions:
How would you fill out this visit?
When would recommend this patient to follow-up?

Case Part C:

Mary returns earlier than her scheduled follow-up, because she had developed a cough and fever for the last 2 weeks. She tells you that she feels very sick. On her clinical review besides the cough and fever she also has night sweats and poor appetite. Her weight is now 52 kg. Right now she is unable to do housework but is able to move around. She has not missed any doses of the cotrimoxazole.

Questions:
How would you fill out this visit?
What are your recommendations for management of her current problem and follow-up?
Case Part D:

Mary returns for her lab results. Her sputums are (-), (++), (++). She still has cough and fever. Her weight is 52 kg and she still is unable to do work at home.

Questions:
How would you fill out this visit?
What are your recommendations for management of her current problem and follow-up?

Completing the HIV Care/ART card side 2: follow-up education, support and preparation for ARV treatment

- The back of the card lets the team keep track of the status of the education, support and counselling for the patient.

- It is important that you remember to review care and complete appropriate items with the patient on the backside of the HIV/ART Card at each visit. If there is a counsellor/educator in your clinic, he or she may do much of this. You should also do this with your patients as time permits.

- You will not be able to cover every item on every visit. You need to prioritise with each patient the most important points to cover in each visit, based on the patient’s clinical and ART history, time available, patient’s ability to absorb information, health status, etc.

  Example: Education, prevention, post-test counselling, disclosure, family/living situation, reproductive choices, and PMTCT might be covered in an early visit and noted on the card. The other rows would be blank. On the next visit, the remaining items would be covered and then a determination would be made with the clinical team to assess readiness for ART.

- Your notes should be legible so that other team members can understand them. If insufficient room on the card, attach a separate sheet.

- Keep your notes up-to-date. Fill them in while the patient is with you. These are not long notes! You can also write additional information in the patient’s exercise book used as a clinical record if he or she has one, but this is not preserved in the clinic as an ongoing record.

- There are three “Date/Comments” columns provided on the card. When you have used all the columns, start a new card and staple it to the previous card.
Basic HIV Education & Prevention: (see section 11 of the *Chronic HIV Care Module*)

- **Basic HIV education, transmission**
  Be sure the patient has received basic HIV education which includes how HIV is transmitted and how to prevent transmission. Review with the patient at each visit until you are confident that he/she understands what HIV is and how it is transmitted and prevented. Record date and comments about HIV education, transmission and prevention.

- **Prevention: safer sex, condom use screening**
  Do not avoid talking about safer sex and discussing condom use with all patients. Have condoms available at each visit and demonstrate correct use as often as necessary. Record if condoms dispensed, and how many. If patient is sexually active, at each visit ask how many condoms used until patient starts to practice safer sex regularly. Create a comfortable patient/provider relationship that allows for open and honest discussion at each visit. Do not preach. Use open-ended questions so the patient will feel encouraged to answer them honestly.

- **Prevention: Household Precautions, What is safe**
  Ensure that the patient understands that HIV cannot be transmitted through household contact and record on card.

- **Post-test counselling, implications of results** (see Annexe A.1 of the *Chronic HIV Care Module*)
  Provide continued emotional support - just one visit for post-test counselling may not be enough. Record on the card until the patient no longer needs counselling. Ensure that the patient understands the implications of their test results and record any areas that need further discussion on the card.

- **Positive living** (see section 11.2 of the *Chronic HIV Care Module*)
  Provide continued education about positive living for PLHAs and record on card.

- **Disclosure, testing partners** (see Annexe A.5 of the *Chronic HIV Care Module*)
  All patients should be encouraged to disclose their HIV status to at least one close family member, friend, or trusted adviser (for example, their minister, teacher or a trusted elder). Record the names of people to whom the patient has already disclosed his or her HIV infection.

  All patients should be encouraged to have their sexual partners attend the clinic to consider testing. Record decisions on card.

- **Family/Living Situation**
  Record specifics of family and living situation that will affect ART adherence and support. Note potential barriers and identify solutions discussed.

- **Shared confidentiality**
  Explain that the clinic has a system of shared confidentiality which means that the patient’s HIV status, record, clinical situation, and treatments are shared amongst the clinical team but not more broadly - this is called shared confidentiality. With the clinical team and record system, it is not possible to have only one health worker knowing the situation of the patient.
<table>
<thead>
<tr>
<th>Follow-up Education, Support and Preparation for ARV Therapy</th>
<th>Date/comments</th>
<th>Date/comments</th>
<th>Date/comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educate on basics, prevention, disclosure</td>
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<tr>
<td>Basic HIV education, transmission</td>
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<tr>
<td>Prevention: abstinence, safer sex, condoms</td>
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<tr>
<td>Prevention: household precautions, what is safe</td>
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<tr>
<td>Post-test counselling: implications of results</td>
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<td>Positive living</td>
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<td>Testing partners</td>
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<td>Disclosure</td>
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<td>To whom disclosed (list)</td>
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<td>Family/living situation</td>
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<td>Shared confidentiality</td>
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<tr>
<td>Reproductive choices, prevention MTCT</td>
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<td>Child's blood test</td>
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<td>Progression of disease</td>
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<tr>
<td>Available treatment/prophylaxis</td>
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<td>Follow-up appointments, clinical team</td>
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<tr>
<td>CTX, INH prophylaxis</td>
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<tr>
<td>ART - educate on essentials (locally adapted)</td>
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<td>Why complete adherence needed</td>
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<td>Adherence preparation, indicate visits</td>
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<tr>
<td>Indicate when READY for ART: DATE/result</td>
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<tr>
<td>Clinical-team discussion</td>
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<tr>
<td>Explain dose, when to take</td>
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<td>What can occur, how to manage side effects</td>
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<tr>
<td>What to do if one forgets dose</td>
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<tr>
<td>What to do when travelling</td>
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<tr>
<td>Adherence plan (schedule, aids, explain diary)</td>
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<tr>
<td>Treatment-supporter preparation</td>
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<tr>
<td>Which doses, why missed</td>
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<td>ARV support group</td>
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<td>How to contact clinic</td>
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<tr>
<td>Symptom management/palliative care at home</td>
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<tr>
<td>Caregiver Booklet</td>
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<tr>
<td>Home-based care - specify</td>
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<td>Support groups</td>
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<tr>
<td>Community support</td>
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</tbody>
</table>
- **Reproductive choice** and PMTCT
  These should be discussed with all sexually active patients, men and women, and their choices recorded. Patient needs to know about both the risk of PMTCT and what interventions are available to reduce this risk. See Chapter 14.

- If appropriate, the decision to have a child’s blood tested should be discussed and recorded.

**Progression of Disease, Treatments**

- **Progression of Disease**
  Starting at the first visit and continuing as appropriate, provide education to the patient on progression of HIV disease and record on card until patient understands how HIV can progress if left untreated or if treatment regimens are not followed. Explain what is available for chronic HIV care and how the clinic works and record on card.

**Available treatments and prophylaxis**

- Following post-test counselling, educate patient about available treatments and prophylaxis against TB and other OIs and record on the card.

- Patients need to be educated on the fact that cotrimoxazole prophylaxis is available and when and why it is used. (Also include INH prophylaxis if this is in the national guidelines.) If the patient is only interested in ART and not cotrimoxazole, note this and educate further. It will be the patient’s decision after education if he or she wants to take cotrimoxazole prophylaxis when they are stage 2 or above.

- **Follow-up appointments, Clinical Team**
  Explain the clinic follow-up schedule and the fact that in your health facility you work as a team on comprehensive HIV care including ART. Because of this, it is not possible to guarantee that the patient will see only one health worker or counsellor on each visit. Tell the patient the names of the other members of the clinical team. They should also know which medical officer is responsible for the clinical team, even if he is not based at this health centre.

**ART Preparation, Initiation, Support, and Monitoring**

- Assess the patient’s understanding and advise them about the essentials of ARV therapy and record on card. This education may take several visits. If there are important misconceptions, note them.

- Since understanding the need for complete adherence is the cornerstone of successful ART treatment for every patient, review at every visit after patient has become eligible for ARV and record on card.

- Adherence preparation takes at least several visits and careful counselling. It should begin soon after a confirmed HIV test or identification of possible HIV infection in a patient who has been identified as a potential candidate for ART and recorded on the card. Indicate the status of adherence preparation and each counselling session. When adherence preparation is complete, record on card.
- Indicate when READY for ART, Result of Clinical Team Discussion
  Record on card when patient is ready for ART - this means that the patient has
  been prepared for ART adherence. This requires several visits. Clinical Team
discussion should be had when a patient is considered to be ready for ART. Record
the results of the clinical team discussion, that is, patient is approved, not approved,
or postponed for ARV. Also record on this line when the medical officer has
reviewed the case and approved initiation of treatment/written the prescription

During both ART adherence preparation and when ART is initiated and supported,
it is important to:

- Explain correct dose to patient and review at every visit and record on card whether
  patient knows when to take the medication.

- Explain when to take ARV drugs and record on card.

- Assess and educate patient on what can occur, how to manage common side
effects and record on card.

- Educate patient on what to do if he/she forgets a dose and record on card.

- Strategize with patient on what to do when he/she travels and record on card.

- Monitor, emphasize, and support the patient's individualized adherence plan at
every visit and record on card. This may involve a schedule, or aids (such as
setting the mobile alarm to beep at the time the medication is due), or a small diary.
Record what the patient is using so that you or your colleague can check on it at
the next visit.

- **Treatment supporter preparation**
  Help prepare a treatment supporter or buddy. If possible, they should come to
  clinic. (See section 8.9 on adherence preparation). Record if this has been
done on the card. Continue to assess the success of the patient’s treatment buddy
plan and record on card.

- Once ART begins, you will be assessing adherence on every visit. How good
  adherence is will be recorded on the front of the card. If any doses have been
missed, record which doses are missed and why. This can help you help the patient
problem-solve and to improve adherence.

- Link the patient to an existing ART Support Group and record on card.

- As appropriate at every visit, ensure and record that the patient knows how to
  contact the clinic. This is particularly important in patients on ART.
Home-based care and support

- Educate patients on the availability of symptom management and palliative care at home. This is available even if they are not on ART.

- Provide Caregiver Booklet and educate on its use. This explains how to provide care at home. Record on card when this has been done.

- Record types and dates of other home-based care provided and any liaisons with home-based care groups. Make sure they know who is providing home-based care in their community.

- Connect and encourage patients and their families to join appropriate support groups and record and review on card as appropriate.

- Connect patient and their families with other existing community support services and record and review as appropriate.

A general principle of good chronic care:

8. Link the patient to community-based resources and support.
Chapter 7: Prophylaxis

Learning objectives

By the end of this chapter you should be able to:

- explain the advantages of cotrimoxazole prophylaxis;
- decide when to start cotrimoxazole primary prophylaxis;
- explain the dose of cotrimoxazole prophylaxis;
- recognise and manage adverse reactions of cotrimoxazole prophylaxis;
- know how to monitor patients on cotrimoxazole prophylaxis;
- follow treatment plan from district clinician for other prophylaxis (INH or fluconazole) [INH prophylaxis has been adapted out in this version—it needs to be re-added in country adaptation].

Maria was hospitalised last week with pneumonia. She is better now but concerned about getting ill again. The nurse talks about cotrimoxazole prophylaxis with Maria. The nurse asks about allergy to sulfadoxine-pyrimethamine (Fansidar) or cotrimoxazole, but Maria has never had an allergic skin reaction to either. The nurse says Maria will have to take 2 tablets, every single day. She says it will reduce the risk of having certain severe lung infections, certain types of chronic diarrhoea and, also, a type of brain abscess that causes weakness or paralysis of one side of the body.

Kato is attending a clinic where there is no cotrimoxazole prophylaxis—they do not have the supplies needed.

Mr. Richard is stage 3 and very concerned about getting sick.

*Does Mr. Richard need prophylaxis?*

Mr. Richard asks several questions to the clinical officer:

*What is the dose of cotrimoxazole for prophylaxis?*

*What does cotrimoxazole prophylaxis do?*

*What should you respond?*
PREVENTION OF OPPORTUNISTIC INFECTIONS

We can decrease the risk of the patient developing some opportunistic infections that can even be fatal. This is done by giving certain tablets to the HIV positive person on a daily basis. This is called prophylaxis.

A good prophylaxis is not expensive or complicated, but can increase the duration and quality of life. The most commonly used prophylaxis is prophylaxis with cotrimoxazole.

OPPORTUNISTIC DISEASES FOR WHICH THE RISK IS REDUCED WHEN TAKING PROPHYLAXIS WITH COTRIMOXAZOLE

- *Pneumocystis* pneumonia (PSP) (this used to be called *Pneumocystis carinii* now called *Pneumocystis Jiroveci*): a type of pneumonia typical among people with low immunity. This type of pneumonia presents with shortness of breath on exertion, dry cough, fever, hypoxemia (decreased level of oxygen in the blood). The prognosis of this type of pneumonia is often bad.
- *Toxoplasma* brain abscess: this disease can cause hemiparesis (one side of the body is weak or cannot move anymore), often together with headache and fever.
- Pneumonia from *S. pneumoniae*.
- *Isospora belli*: this type of micro-organism is responsible for some cases of chronic diarrhoea with weight loss.
- *Salmonella* species: gastro-intestinal symptoms and fever.

Read the guidelines for cotrimoxazole prophylaxis on section 7.2 in *Chronic HIV Care Module*.

CRITERIA TO START COTRIMOXAZOLE PRIMARY PROPHYLAXIS IN ADULTS

All HIV+ people with WHO clinical stage 2,3,4 or with a CD4 count less than 200 cells/mm³ should start cotrimoxazole prophylaxis. First ask about a previous history of sulpha allergy - these patients should not be given cotrimoxazole.

DRUG REGIMEN FOR COTRIMOXAZOLE PROPHYLAXIS

cotrimoxazole 480 mg, 2 tablets daily  
OR  
cotrimoxazole 960 mg, 1 tablet daily

DURATION OF PRIMARY PROPHYLAXIS

If an HIV+ patient has no access to ART, the primary cotrimoxazole prophylaxis should be taken for the rest of his/her life.

If the patient has access to antiretroviral therapy, the cotrimoxazole primary prophylaxis can be stopped when the CD4 count has increased to 200 cells/mm³, and remains more then 200 cells/mm³ for at least 6 months.
COTRIMOXAZOLE PROPHYLAXIS SIDE EFFECTS

Explanations of serious side effects (section 7.2 in the Chronic HIV Care Module):

In these cases, cotrimoxazole should be stopped and the patient referred.

- **Steven Johnson reaction**: a very severe drug reaction that can be fatal if not recognised. There is involvement of the eyes and mucosa of the mouth. The skin lesions can look like burns with blistering and peeling. Patients lose fluids (as they do from a burn) and can go into shock. These patients need to have cotrimoxazole stopped and should be referred urgently to hospital.

  (Look at photo 9S in the Acute Care photo booklet)

- **Fixed drug reaction**: one or several dark areas on the skin. They disappear when stopping the drug. They reappear on the same location when restarting the drug.

  (Look at photo 9R in the Acute Care photo booklet.)

- **Other new generalised drug rashes**: If the patient has peeling or involves the eye or mouth or are associated with fever, stop and refer.
  If there is no peeling, no fever and no eye or mouth involvement, just stop the drug. Follow-up the next day.

- **Liver failure**: This is detected by jaundice (yellow colour of the white of the eyes) can appear. Stop all drugs. Call for advice or refer.

- **Haematological failure**: in rare cases, cotrimoxazole can suppress the bone marrow. The bone marrow is responsible for making new blood. This can present in several ways:
  - the patient develops severe anaemia (looking pale or having low haemoglobin), and/or
  - the patient develops a decrease in white blood cells (leading to infections) and/or
  - the patient develops easy bleeding due to a decrease in blood platelets, which are responsible for clotting of the blood.
MONITORING COTRIMOXAZOLE

- In the beginning, follow-up every month. Later, if no problems occur and if the patient takes the drugs correctly, follow-up can be done every 3 months.
- Follow-up visits should include monitoring for side effects, education of the patient on the importance of taking the drug.
- Use the 5 As to prepare the patient for cotrimoxazole and to follow-up.
- Attending clinic regularly for scheduled visits (adherence to care) and adhering to daily cotrimoxazole prophylaxis are good preparation for ART. These visits also provide the opportunity to monitor the patient’s clinical stage and their medical eligibility for ART.

WHEN CAN YOU STOP COTRIMOXAZOLE PROPHYLAXIS?

If the patient is on ART, you need to continue cotrimoxazole until the CD4 count is more than 200 cells for 6 months. When CD4 is this high the patient no longer needs the protection from cotrimoxazole. Then you can stop the prophylaxis.

Unfortunately at this time there are no clinical criteria for when to stop cotrimoxazole. This is difficult to judge because the CD4 comes up slowly and not at the same speed in each patient.

FLUCONAZOLE PROPHYLAXIS

You may also see some patients on fluconazole prophylaxis after cryptococcal meningitis. Use the section 7.3 in the Chronic HIV Care Module

EXERCISE 7-1

1. A 25-year-old woman comes to the consultation. She has been referred from the testing centre with a positive test for HIV. She has white patches in her mouth and weight loss. Does she need cotrimoxazole prophylaxis? How many pills will you give to the patient? What will you explain?

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2. A 34 year old man comes asking for ART. He has known he is HIV+ for 2 years. He is bothered by seborrhoea and recurrent mouth ulcers. He had herpes zoster 2 years ago. He has no signs of stage 3 or 4. What would you respond? What can be offered?

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Learning objectives:

By the end of this module you should be able to:

- use the 5As to prepare patients for ART adherence;
- assess the patient’s goal for today’s visit;
- assess the patient’s understanding of ART;
- assess the patient’s interest in receiving ART;
- give complete advice to the patient about HIV/AIDS and ART;
- check that the patient is willing and motivated and agrees for ART;
- help the patient to develop the resources/support/arrangements needed for Adherence;
- make arrangements for follow-up after the ART preparation session;
- discuss case with clinical team to propose patient to start ART.

Maria starts to have recurrent white patches in the mouth.

Which treatment would you give for these white patches in the mouth? Where do you find the treatment? In which stage is Maria now?

The nurse looks on section 6.1 of the Chronic HIV Care module. There, it is indicated to go to the Acute Care module in case of new symptoms. She finds the treatment for oral thrush on page 21 of the Acute Care module.

Every time, the nurse has treated the white patches with nystatin, but Maria has frequent relapses.

The nurse starts to discuss ART with Maria.

What things could you discuss on the first preparation for ART?
One month later, Kato comes back from the hospital. He is still weak and thin, but looks much better then before and his weight has increased. The fever and cough have decreased, but have not yet disappeared. The referral letter said that Kato has disseminated TB. He takes TB treatment and cotrimoxazole prophylaxis, as well as chlorpheniramine for the itching.

The nurse starts to discuss ART with Kato.

*What things could you discuss on the first preparation for ART?*

The nurse has invited Mr. Richard for an ART preparation session (his CD4 count was 150; he is in clinical stage 3).

She assesses what Mr Richard already knows about ART. Mr Richard has some friends on ART, so he knows some things.

However, some of the information he received through his friends was not correct. The nurse corrects some of the wrong ideas and she adds some more information.

She makes sure Mr Richard is willing to receive therapy and starts to think over with him ways to implement adherence in his life. She does not give all information at once, but she arranges a date for another session.
ASSESS

Assess the patient's goals for today's visit

"Is there anything special about HIV/AIDS or ART you would like to address in today's session?"

Assess understanding of ARV therapy (ART)

Assessing whether the patient understands ART should include specific questions. Asking general questions like: "Do you understand everything concerning antiretroviral therapy?" is not very useful. Most of the patients will answer "yes" to this question, even if they do not understand all of it. The best way is to ask questions that require more than a 'yes' or a 'no' from the patient. Questions that make the patient explain in his own words what he knows are good to assess the patient's understanding. It is important to make the patient feel comfortable, not as if s/he is taking a test! If the patient has misunderstood or forgotten some information, reassure the patient that this is normal, and re-explain.

Questions that can be asked to assess the patient's understanding are:

"What do you know about HIV/AIDS and ART?"

If necessary, more specific questions can be used, because big questions such as "what do you know about HIV/AIDS and ART?" can sometimes overwhelm the patient. In that case he would say "nothing", while he might know a lot when you ask smaller but specific questions:

- What are the benefits of ART?
- Does ART cure patients from HIV?
- How long do you have to take ART?
- What is the effect of ART on the body's defence?
- Why is it important to come regularly to the health centre when you are taking ART?
- What do you know about side effects of ART?
- Why is it important not to miss a dose when you take ART?
- What happens if you do not take ART correctly?
- Why is it not good to combine ART with other drugs without consulting the health centre staff first?
Assess interest in receiving therapy

Not all patients are interested in receiving ART, even if they are medically eligible for ART. Patients may have other urgent preoccupations in their life that make they want to postpone initiating therapy.

That is why it is necessary to assess (in depth) to be sure that the patient is interested in receiving ART.

ADVISE

"I have some information about HIV/AIDS and ART. Would you like to hear it?"

Give the patient advice on the following topics (use the flipchart when this is helpful):

- HIV illness and expected progression (locally adapted, using language your patient can understand)

Asymptomatic period of some years after infection.
Opportunistic infections that gradually become more serious, because HIV is attacking the body’s defence.

It is good to use drawings or a flipchart to explain these topics:

- You can use the story of Flavia and Julio (in Chapter 11) to explain the natural course of the diseases.
- You can use the drawings of the fighting men in chapter one to explain opportunistic infections.

ARV therapy (ART)

- Benefits of ART—lifesaving drugs. Your life depends on taking them every day at the right time.
- Very strong medicines
- The pills do not cure HIV— they just control it
- The pills do not prevent transmission of HIV to others - you must still use condoms and practice safer sex. The therapy can never eradicate the virus from your body.

You forget and remember within 4 hours, it is OK to take it then. The next dose should be taken at the usual time.

Must be taken at the right time, every 12 hours.
If you stop you will become ill again (not immediately—it may take months or even years as your immunity drops again)
Possibility of side effects and drug interactions
Importance of disclosure of HIV+ status (Annexe A5 in Chronic HIV Care module)
Importance of testing partner and children
Drugs must not be shared with family or friends—patient must take the full dose.

Do not overwhelm the patient with too much information at once. The patient needs time to think about and digest some information, before he will be able to concentrate on further information. That is why it is good to split the advice over several visits, and indicate on the education side of the patient’s Treatment Card the information that has been given already.
When you give advice, it is necessary to evaluate the patient's confidence and readiness to adopt the treatment. If you notice the patient is not paying attention anymore, or does not make eye-contact with you anymore, it is good to ask if there is a reason for this. If you have the impression you lost the patient's attention, it might mean he is overwhelmed by the amount of information. Or it could mean the patient starts to think that all of this is too difficult for him.

Establish that the patient is willing and motivated and agrees to treatment, before initiating ARV therapy.

When agreeing with patients to start ART, it is important to check whether the patient is willing and motivated. The patient is the one that must take the responsibility for taking the medication twice daily every day. S/he must very motivated to take the medications and be ready to make the necessary life adjustments to do this.

"After hearing all the explanation and advice, how do you think you could take this kind of treatment?"

Besides the answer to this question, it is good to also look at some objective measures to check the motivation. Do not rely only on your personal feeling. Studies have shown that the health care worker's impression does not always correspond with the real situation concerning motivation and adherence.

That is why it is useful to check:

- **Has the patient demonstrated ability to keep appointments and to adhere to other medications?**

  Whether the patient comes on time on the appointments (check book and patient chart) and takes other treatments (for example cotrimoxazole prophylaxis) correctly (ask to repeat how he takes it, count pills). Does the patient have a history of non-adherence, for example a TB defaulter. This should not exclude him but means that more work is required to prepare for ART adherence.

- **Has the patient disclosed his or her HIV status? If not, encourage him or her to do so. Disclosure to at least 1 person who can be the treatment supporter is important.** Overall, supporting disclosure is important (see page H60 for ways to help patients with disclosure or ask a counsellor in clinic to help).

  Does the patient have a treatment supporter? Note that this might not be possible for everyone to bring their treatment supporter with them to clinic—people who live far and need to pay transport for two people might not be able to do so for instance. So just not bringing a treatment supporter is no reason to exclude someone from ART.

- **Does the patient want treatment and understand what treatment is for?**

- **Is the patient willing to come for the required clinic follow-up?**
Explore what is needed to assist the patient with ART:
"What problems might arise when you follow this plan?"
"What questions do you have about this treatment or how to follow this plan?"

Help the patient develop the resources/support/arrangements needed for adherence:

- **Ability to come for required schedule of follow-up**

  It is crucial to discuss this in detail. If the patient lives far away, it is necessary to ask how they will come. With a family member that has a car? Will the family member be available to come regularly to the consultation, also if there is an unexpected complication? With public transport? Will you have money available to pay for public transport?

- **Home and work situation that permits taking medications every 12 hours without stigma**

  Some people might be away from home for more than 12 hours a day, and be surrounded by people all the time. It is important to check whether the patient will be able to cope with this situation. This means the patient always needs to carry some pills with him (in a pocket), and might need to find a place to take the drugs without others watching, and maybe a watch with a discrete alarm to remind the time when pills need to be taken.

  It is important to help the patient figure out routines to set up before starting ART that fit regular pill-taking with the rest of their life.

- **Regular supply of free or affordable medication**

  It is important to guarantee a continuous supply of drugs. This is a substantial commitment. Taking drugs for a limited time or with interruptions will create resistance. For patients buying their own drugs, it is important to assess the viability of their financial resources.

- **Supportive family or friends**

  Stigma and discrimination in the family may be a barrier to adherence. A family that knows about the diagnosis and are willing to remind the patient to take the drugs or to support the patient in moments where adherence is difficult can help support adherence.

- **ART adherence support group**

  These can be very important to support adherence. Community based organizations may organize these groups or someone on your clinical team can help your patients set up such groups (see counselling course).

- **Treatment supporter - prepare him/her** (section 8.11 in *Chronic HIV Care Module*)
This is a very important person for treatment success. It is important that this person be prepared for their role, either in the clinic or by a community group supporting ART.

**ARRANGE**

When patient is ready for ARV therapy, *discuss at clinical team meeting then make a plan.*

It is not possible on the same visit that you decide the patient is medically eligible for ART to prepare the patient for adherence. It takes at least 2 to 3 visits and the involvement of others on the clinical team and a treatment supporter.

If the patient needs another adherence preparation session, arrange a follow-up to reinforce key messages.

Arrange an appointment with the ART support group if the patient wishes so.

Record the information you gave during this visit on the back of the Treatment Card, so you can adapt the next consultation.

**Discuss case with the clinical team to recommend the patient to start ART.**

*ART is a long-term commitment of the clinical team and the patient and both need support and help from treatment supporters and others in the community.*

If this is the last adherence preparation session, and the patient is ready and eligible for ART, *discuss at clinical team meeting and then make a plan.*

Make sure the patient knows when the next appointment is.

**EXERCISE 8-1**

How might you respond if a patient asks:

1. "How can I possibly remember to take a drug twice a day at the same time for ever?"

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2. "What is the purpose of taking such a complicated treatment if I will not get cured?"

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3. "What if I go away for a few days and I forget to take the drugs with me?"

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4. "My wife is HIV+ as well and she has not been given ART. How can I take it?"

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5. "You are talking about side effects which might really bother me, how can I take drugs that make me feel so bad?"

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6. "What if other people can see that I am taking ART?"

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7. "What if people see me when I come to get my drug at the clinic?"

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8. "I have heard that in America, ART is not so complicated. They give 1 pill per week. Why do you want to give me pills to take twice a day?"

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_____________________________________________________________________
9. "You are saying that I need to tell at least one person that I am HIV+. I actually change my mind about telling another person. I do not need anybody to support me. I can do all on my own."

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10. "My wife - who will be my treatment supporter - does not have time to come to meet you since we have 3 children and one of them is sick."

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EXERCISE 8-2

Role Play for Preparation for Adherence to ART

Part A

1. Provide one or two examples of conditions which can be a problem for adhering to ART.

2. The facilitator will write all examples on the flipchart.

3. The facilitator will go over the examples and explain what is relevant or not.

4. Assisted by the facilitator, you will see which of the examples provided could be solved by the 5As.

Part B

1. Together with the facilitators, among the above examples, you will choose 3 which you could most frequently encounter when preparing a patient for adherence to ART.

2. The facilitators, or one facilitator and one participant or EPT (after a brief explanation), will do a role play (taking into consideration the examples selected) using the 5 As (section 8.9 of the Chronic HIV Care Module).

Please write at least one example for each of the 5As discussed during the role play.
Part C

1. Write at least one new example for each of the 5As. You can create your own case.

   ASSESS:

   ADVISE:

   AGREE:

   ASSIST:

   ARRANGE:

2. The facilitator will choose 1 or 2 good examples among those you wrote.

3. The facilitator will write the selected examples on the flipchart and will discuss them with the group.

Part D

1. The facilitators or one facilitator and participant will do a role play for preparation to adherence, using only 3 of the 5As (skipping advise and agree).

   Please write down:

   WHAT THEY HAVE SKIPPED:

   WHAT YOU WOULD HAVE DONE:
Chapter 9: Initiate first-line ARV regimen at first-level facilities in patients without complications

Learning objectives

By the end of this module you should be able to:

- explain medical eligibility for ART;
- explain why decentralization of ART is important;
- describe the 7 requirements to initiate ART in patients without complications;
- describe how to treat/stabilize opportunistic infections before initiating ART;
- describe first-level facility TB management and ART;
- explain how to decide medical eligibility for ART if CD4 is available;
- explain how to decide medical eligibility for ART if CD4 is not available;

Maria has gone through several sessions, talking about HIV/AIDS, ART and adherence. She always comes on time for the appointment, and takes her cotrimoxazole correctly. She has a treatment supporter (a neighbour). The nurse and Maria feel she is now ready for ART.

The nurse has gone through several preparation sessions for ART with Kato. It was hard to convince Kato to wait with ART until he was stable and prepared, but the nurse managed. He has gained more weight; the fever and cough have completely disappeared. He has finished the first two months of TB treatment but has not gained weight. The itching rash on his arms is still present, as well as the angular cheilitis.

The district medical officer on the team has visited the health centre to assess Kato and decided Kato needs to begin co-treatment with TB treatment and ART. The medical officer has prescribed ZDV - 3TC - EFV.
Is Mr. Richard eligible for ART?
Does Mr. Richard fit the 7 criteria and the 7 requirements?
What drug would you prescribe?

It has been decided that Mr. Richard is eligible for ART, because of his low CD4 count. Mr Richard fits the 7 requirements.
The nurse recommends d4T-3TC-NVP. The medical officer from the district clinic, on her clinical team, has reviewed the case and written the prescription. She tells him to take 1 tablet that contains the 3 drugs in the morning, and then a separate tablet of d4T and 3TC in the evening, for the first 2 weeks only. She asks Mr. Richard to repeat the information to make sure he understood.
Mr. Richard asks whether he has to continue to take the cotrimoxazole prophylaxis, now that he is on ART.

What will you answer Mr. Richard?
The nurse tells Mr. Richard to continue the cotrimoxazole until his CD4 count has gone up to more than 200 cells/mm³, for at least 6 months.

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**Requirement 1:** HIV positive with written documentation (start ART only in patients with a written document of a positive test)

Patients should come to the health centre with written documentation of a positive HIV test. If the patient has had a positive HIV test at another facility, but does not have written documentation, the test should be repeated. Patients should not start ART if there is only a clinical suspicion of HIV infection. There is also the possibility that a few patients may want to get ARV drugs to sell them. Mistakes have also been made in assuming that a patient with severe wasting has AIDS; other conditions can also cause wasting in adults.

**Requirement 2:** Medical eligibility - start only patients with medical eligibility for ART

See the WHO clinical staging in section 3.4 of the *Chronic HIV Care Module.*

Starting ART is never an emergency
If the CD4 is still high and you do not have signs and symptoms of WHO clinical stage 3 or 4, you should not start ART yet. It is not useful to start ART too early because it will be costly and the quantity of virus is low in the first years (which does not mean the patient can not transmit the virus!), and the patient is not yet very sick. If treatment is started too early, then patients will only experience side effects and no beneficial effect.
The patient is medically eligible for ART if:

**If CD4 testing available:**
- CD4 < 200 at any stage or
- WHO clinical stage 4 (no matter what CD4 count) or
- WHO clinical stage 3 (taking into account CD4 less than 350). National guidelines vary; insert your national guideline:

**If CD4 testing not available:**
- WHO clinical stage 3. National guideline may vary as to which patients in stage 3 are started. Some specify certain patients or, as in Uganda, more than one sign or a repeated/chronic problem. Insert your national guideline concerning stage 3:

  ____________________________________________________________

- WHO clinical stage 4

**Requirement 3:** Patient fits criteria to be started on ART at first level facility. This means that you can answer NO to all of the 7 questions in the box.

1. **DOES THE PATIENT HAVE A SEVERE ILLNESS REQUIRING REFERRAL OR A WHO CLINICAL STAGE 4 CONDITION?**

- As a general rule, we can say that we should not initiate ART during a severe acute opportunistic infection or other severe illness.

  ART should not be started before serious acute opportunistic infections are under control, because patients already have to take many drugs for the opportunistic infection. There may be interactions between the different drugs, patients may vomit their drugs, and they may die from their OI.

- ART should not be started at the level of the health centre for patients who are in WHO clinical stage 4 or who have certain unexplained symptoms.

Patients who are in WHO clinical stage 4 can suffer many complicated OIs. These OIs can often not be recognized, or the diagnosis cannot be confirmed at the health centre level, or the treatment for these conditions might not be available.

When ART is started in patients with these unrecognised or untreated opportunistic infections, the start of ART can cause a strong reaction with the unrecognised opportunistic infection. This makes that symptoms suddenly worsen, and the patient can even die (see Chapter 11).
That's why sick patients in stage 4 or with unexplained symptoms of persistent fever, cough, headache or neurological signs should first be referred to assess and treat these difficult types of OI, before starting ART.

There are 2 exceptions to not starting patient with active clinical stage 4 conditions on ART at the health centre:

- **chronic herpes simplex** If aciclovir is available, this should be used to try to resolve the herpes simplex; if it cannot, then the patient should be started on ART.
- **oesophageal thrush** that can be treated (patient can swallow fluconazole and has responded). These conditions should not be referred. ART can be started at the level of the health centre for these cases.

The most important thing to remember is not to start ART at the level of the health centre in a patient with persistent fever (even if it is only intermittent), unexplained cough, neurological symptoms, or an acute stage 4 condition except chronic herpes simplex and oesophageal thrush if the patient can be treated (the 2 exceptions).

### 2. IS THE PATIENT CURRENTLY ON TB TREATMENT?

TB is an opportunistic infection that occurs frequently in HIV+ patients. In the previous paragraph, we mentioned that OIs should be treated before starting ART.

However, TB is a special OI. The duration of treatment for TB is usually at least 8 months, and during this time, dangerous OIs can occur if the patient has very low immunity.

On the other hand, drug interactions between TB drugs and ART can occur, and the number of pills the patient has to take if both TB and HIV are treated at the same time, is very high. The interactions between ART and TB treatment occur mainly during the intensive phase of TB treatment, when the treatment contains rifampicin. The interactions can damage the liver or make some ARV drugs less effective.

The decision on giving ART and TB drugs together needs to be made by the doctor or medical officer.

The patients who need to be referred for the doctor or medical officer to make a decision on how and when to give TB and HIV treatment together are:

- Patients who are already on ART and develop TB (new positive TB sputums or other signs suggesting TB). The doctor or medical officer needs to decide on how to co-treat these patients. This needs to happen right away if there are positive sputums so that TB treatment can begin. The diagnosis of smear-negative TB and extrapulmonary TB also needs to be made by the medical officer.

- HIV patients who are on TB treatment for pulmonary TB (smear-positive or smear-negative) who have ANY of the following:
o losing weight on treatment
o has or develops on treatment signs of clinical stage 4
o develops on treatment either thrush, pyomyositis, recurrent pneumonia, persistent diarrhoea, or new prolonged fever

• HIV patients with extrapulmonary TB on treatment

• Any TB patient with CD4 less than 350. The doctor or medical officer will need to make a decision as to when to start ART.

Patients who do NOT need to be referred are:

• **Smear-positive pulmonary TB who are doing well on treatment.** This means that they are without any other signs or symptoms of clinical stage 3 or 4 and they gain weight on treatment. For these patients, complete the entire TB treatment and start ART after completing TB treatment if the patient is eligible. No referral is needed in this case. This is important because referral can be difficult for the patient and interfere with the support system for directly observed treatment (DOTS).

• **Patients who have completed TB treatment for either pulmonary or extrapulmonary TB.** These patients can be started on ART if they have no new symptoms and meet the requirements for ART.

• **TB patients with a CD4 count more than 350.**

→ Do not give ART and TB drugs together without consulting the doctor or medical officer for advice about interactions with the current regimen. A switch in ARV regimen might be necessary.

3. **IS THERE PERIPHERAL NEUROPATHY?**

Patients with peripheral neuropathy (burning or tingling or numbness in the feet or hands), should not receive d4T which causes nerve toxicity, because this may worsen the problem of tingling and numbness. That's why patients suffering from this condition should be referred to the medical officer to start another first-line ARV regimen such as ZDV-3TC-NVP, or if this is not possible, you should call for advice.

4. **IS THERE JAUNDICE OR KNOWN LIVER DISEASE?**

Patients with a liver disease (for example presenting with yellow eyes) should not receive a regimen that contains drugs that can cause liver toxicity, like nevirapine. That's why patients suffering from those conditions should be referred to a doctor or medical officer to start an adapted ART regimen.

5. **DOES THE PATIENT HAVE A CHRONIC DISEASE LIKE DIABETES OR HEART DISEASE?**
Chronic diseases that require more expertise in deciding on how to give ART include diabetes mellitus, epilepsy, kidney disease, and heart disease. These patients should be referred to the doctor or medical officer before starting ART.

6. IS THE PATIENT A CHILD?

ART should not be started in the health centre for children, because:

- Children have different criteria to start ART
- CD4 values in children have a different meaning
- Certain antiretroviral drugs cannot be given to young children/infants.
- The dosing for children is complicated, and adapted formulations for children are not available at the health centre level, at least initially. Children should be started on ART by the doctor or medical officer and then can be followed at the health centre.

7. IS THERE PRIOR ART USE (EXCEPT NEVIRAPINE FOR PREVENTION OF MOTHER-TO-CHILD TRANSMISSION)?

Always take a history of what kind of medication patients took before, especially ART. Do this even if the patient does not mention it spontaneously.

Patients who have taken ARV drugs before may already be resistant to certain drugs (this means that the virus might have made some changes in its structure that make the drugs not effective anymore). In that case, the usual first line regimen might not work anymore.

This is why patients with previous ART experience should be referred to a doctor. The doctor will find out to which drugs the patient is probably resistant by taking a detailed history. This information will help the doctor to find a special regimen that might still be effective for this patient, while maybe the usual first-line regimen would not be.

An example: a patient who took 3TC-d4T-NVP for 2 years, and started to have symptoms of OI again in the end, should probably not be restarted on the same regimen, because it seems he has failure of therapy, maybe due to resistance.

Another example: a patient who took only 2 ARV drugs instead of one for 12 months. The virus of this patient will have had a lot of opportunity to make changes in its structure, and develop resistance, not only against these 2 drugs, but also against drugs from the same class.

The only exception to this rule is a mother who took one tablet of nevirapine at onset of labour in the framework of prevention of mother to child transmission. We do not consider them as ART experienced, and they can receive the standard first-line treatment, without referral.

It is very important to ask thoroughly about previous ART experience in all your patients. If patients have previous ART experience, they should be referred to a doctor who has been trained in ART.
Requirement 4: Any opportunistic infection has been treated or stabilized

What can be done at the health centre, or by the nurse or clinical officer on the district team, to accomplish this is summarized in the table on section 8.2 of the Chronic HIV Care Module. This requires some familiarity with managing acute illness caused by opportunistic infections in adults. You may need to refer either to the IMAI Acute Care guidelines or to national adult clinical guidelines.

When a patient is severely ill or has any severe illness (pink classification) in the IMAI Acute Care guidelines, the patient should not start ART right away, because the patient is so unstable that the patient cannot be prepared for ART, or the patient may die from the OI, or the pill burden may be too high, or interactions between drugs can occur. That is why the patient should be referred. Once the patient is stable, it can be decided at district or hospital level to start ART. In that case, the patient will be referred back with a treatment plan indicating when to start ART and what regimen to use.

Many OI can have non-typical presentations in people with low immunity. Pulmonary TB can present like pneumonia, because often there is no positive smear in HIV+ patients, and there might be a temporary and small improvement by giving antibiotics. Starting ART in a patient with unrecognised and thus untreated TB is not beneficial and can have a poor outcome: the patient's condition might worsen after initiation of ART. That is why ART should not be started until two weeks after completing a treatment for pneumonia, to be sure it was not TB. If the patient has TB, the TB treatment should be started before starting ART.

Malaria, mouth/throat infections, sexually transmitted infections (STI), urinary tract infections (UTI), reactive lymphadenopathy (enlarged and tender lymph node near an infection), and oesophageal thrush need to be treated first, before starting ART. The duration of these treatments is short (hence not a high risk of developing new OIs in the mean time). It is better not to start different treatments (antibiotics and ART) together. Starting antibiotics together with ART represents a big number of pills; this may confuse the patient so he doesn't take the ART well. And if side effects occur it can be difficult to sort out which drug has caused them.

Never start ART in a febrile patient. Extra-pulmonary TB and other OIs can be mistaken for malaria, because they can present with fever and some atypical symptoms. Starting ART in patients with unrecognised and thus untreated OI can have a bad outcome: the patient may become sicker after initiation of ART. The patient may become sicker than before the ART. If a patient has fever, treat according to acute care. If the fever persists, do not start ART, but refer for further assessment and treatment of OI first.

Starting ART in patients with a drug reaction is not beneficial. ART itself can cause drug reactions, so when ART is started when the patient suffers from a drug reaction due other drugs, it might be difficult to recognise and manage drug reactions due to ART.
Certain opportunistic infections will not respond to any treatment, only ART will help. In these cases it is useless to wait to start ART until the OI resolves, because they will never resolve. Some examples:

- Itching of the skin (prurigo)
- Persistent diarrhoea that has already been treated empirically
- Non-severe anaemia that has not responded to treatment. This is often anaemia of chronic illness due to the HIV virus itself.

If the patient has recently been hospitalized and fully treated for cryptococcal meningitis, or toxoplasma brain abscess and has no signs or symptoms, you can start ART. It is best to confirm the treatment plan with the doctor or medical officer. Do not start ART in patients with toxoplasma or cryptococcal meningitis if they did not complete the treatment yet or if they are not symptom-free. This could worsen the problem. Call for advice.

**Requirement 5: Patient is ready for ARV therapy**

This is the most important and difficult requirement. Preparation for ART and assessment of patient's readiness to start ART is described in chapter 8.

ARV treatment is rarely an emergency. It is essential for adherence that a partnership be formed with the patient where he or she takes responsibility for taking ARV drugs regularly. It will almost always take several visits to arrive at this readiness. When the patient is ready for ART, this should be discussed at a clinical team meeting. If the decision is that the patient is both eligible and ready, put the date next to this in the upper right corner of the HIV Care/ART card.

**Requirement 6: Supportive clinical team prepared for chronic care**

People living with HIV/AIDS need a good chronic care with follow-up over a long period of time.

The clinical status in the current consultation has to be compared with the clinical status in the previous consultation, to see whether the ART is effective. This means that patient charts need to be filled out on every consultation and be accessible for your colleagues working in the same team.

People living with HIV/AIDS may encounter many difficulties: stigma, difficulties in taking the drugs correctly, side effects of drugs, serious opportunistic infections that need referral to the hospital and many others. One single nurse can not respond to all these needs. That is why providing care for people living with HIV/AIDS requires a team: doctors or medical officers to refer to or call for advice for difficult cases, a nurse or clinical officer to provide acute and chronic care, counsellors and lay providers to provide treatment education and support,
someone to dispense the drugs correctly, and community support for ART and other home-based care.

Providing ART requires all kind of different providers to work together, and to be prepared to do so. The purpose of this course is to prepare the clinical team so this requirement is met.

Requirement 7: Reliable drug supply

Starting ART for a short period of time does not make any sense. The virus remains in the body forever. Continuous levels of antiretroviral drugs are needed to halt the virus making new copies.

Interruptions because drugs are out of stock is not acceptable for ARV drugs since this can create resistance. A virus that is resistant will not be sensitive to the drugs anymore, and the patient will become sick again. In addition, patients who are resistant may spread the resistant virus to others. These newly infected persons will be resistant to ART (and thus not get better with treatment), even if they have not been on ART before.

If one drug is out of stock, all drugs must be stopped at the same time.

Recommending ART, prescribing, referral to the district clinician to start ART

If all patients need to be referred to the district hospital or speciality ART clinic for ART prescriptions this will reduce access and lose some patients. The responsible doctor or medical officer could visit the health centre to review the patients without complications who fit the requirements, then start treatment (consultation with later record review might also be considered, based on a standing order). This requires discussion and planning for each district team.

See Chapters 14 and 15 for special considerations for ART in pregnant women and children.

EXERCISE 9-1

1. An HIV+ patient with chronic fever and a CD4 of 50 cells/mm³ comes to the health care centre. What will you do?
   A. refer him/her for assessment of the fever before starting ART
   B. start ART now, because the ART will decrease the fever
   C. give antimalarial drugs and start ART at the same time
2. An HIV+ patient has headache and fever since 1 week. His CD4 is 20 cells/mm³. What will you do?
   A. refer him for assessment of the headache and fever before starting ART
   B. start ART now, because the ART will decrease the headache and fever
   C. give antimalarial drugs and start the ART next week, even if the patient still has headache and fever.

3. A patient has oral thrush and chronic diarrhoea. You gave empirical treatment for the diarrhoea and it resolved. You gave miconazole gumpatch for the oral thrush and it disappeared. The CD4 of the patient is 100 cells/mm³. He has no other symptoms. What will you do?
   A. refer the patient for assessment before starting ART
   B. start preparing the patient for ART in the health centre
   C. observe the patient regularly, but not start ART yet, because the patient has no criteria to start ART

4. A patient had Herpes Zoster on the left side of the chest last week. His CD4 is 168 cells/mm³. He has no other symptoms, and the herpes lesions start to heal. What will you do?
   A. refer the patient for assessment before starting ART.
   B. start preparing the patient for ART in the health centre
   C. observe the patient regularly and give cotrimoxazole prophylaxis, but not start ART yet, because the patient has no criteria

5. An HIV+ patient has been diagnosed with pulmonary TB. His CD4 is 123 cells/mm³. What will you do?
   A. tart TB treatment and refer the patient for ART after the TB treatment is finished
   B. start TB treatment and call for advice on which ART to start
   C. start ART now, and treat TB later

6. An HIV+ patient has an itchy papular skin eruption, mainly on arms and legs, for several months. He has no other symptoms. You have no CD4 available. What will you do?
   A. start preparing the patient for ART now
   B. not start ART yet, but start cotrimoxazole prophylaxis, because there are not enough criteria to start ART
   C. refer the patient for assessment

7. An HIV+ patient who has been treated for chronic genital herpes simplex comes to the consultation. There are no CD4 counts available in your setting. What will you do?
   A. start preparing the patient for ART now
   B. not start ART yet, because there are not enough criteria
   C. refer for further assessment

8. A new patient comes to the health centre because he is HIV + and says that he needs to start ART right away. He tells you that he had a "brain infection" last year. You now have ART available.
   A. start preparing the patient for ART now
   B. ask for written documentation of his HIV test and previous records
   C. refer him for assessment
9. An HIV+ patient recently finished treatment for oesophageal thrush. You start preparing for ART, and she tells you that she took it when she was pregnant so she knows all about it. You should:

A. refer her to the district clinician  
B. start her on the same ART combination  
C. start preparing her for ART and find out which ARV drugs she took when she was pregnant.

10. An HIV+ patient has a CD4 count of 150 and sores at the corner of his lips. He also says that he has lost weight. He tells you that he know he needs ART, because it helped him put on weight before. What will you do:

A. refer him to the district clinician  
B. start preparing the patient for the same combination of ART that worked before  
C. give him cotrimoxazole and tell him that he is not medically eligible for ART yet.

EXERCISE 9- 2

Your facilitator will give you a checklist that can help you practice deciding whether the 7 requirements for starting ART have been met.

Footnote 1:

In general, the guidelines on when to start ART in patients under TB treatment consider the following:

’Is the risk of developing dangerous OI more important then the disadvantage of drug interactions and high pill burden?’

The answer to this question depends on the immunity of the patient:

→ Very low immunity (CD4 less than 200) and patient takes TB treatment. The patient is very much at risk to develop serious OI and ART should not be postponed for more than some weeks. The medical officer must consider which ART regimen should be started that is compatible with TB treatment.

→ Low immunity (CD4 between 200 and 350) and patient takes TB treatment. The risk to develop serious OI is still present, but we can afford to wait for 2 months. Doing that, we avoid a high pill burden and drug interactions with rifampicin.

Start ART only after the intensive phase of TB treatment (the medical officer will decide on which regimen in case the continuation phase still contains still rifampicin).

→ Moderate immunity (CD4 more than 350) and the patient takes TB treatment. The patient is not so much at risk for developing serious OI, and s/he can wait to start ART until the TB treatment is finished.
Learning objectives

By the end of this chapter you should be able to:

- understand the four first-line ARV regimens;
- determine correct dose for the four first-line ARV regimens;
- advise patients on how to take each of the four first-line ARV regimens.

THE FOUR FIRST-LINE REGIMENS

First-line ARV regimen instructions: these are in section 8.5 of the Chronic HIV Care module and the Patient Treatment Cards in Annex D. You will learn how to use these instructions to support patients to take ART. There will be a Patient Treatment Card for each first-line regimen.

Look at the treatment plan in the upper right hand corner of the HIV Care/ART Card to identify the ARV drug regimen.

Then, use the chart on FIRST-LINE ARV REGIMEN INSTRUCTIONS to determine:

1) How many times the patient takes each medication in a day; and

2) What is the dosage?

All the information you need is on the chart.

The following is an example of the instructions on how to take the drugs on the treatment chart for a patient on the d4T-3TC-NVP (stavudine–lamivudine–nevirapine) regimen from section 8.5.
DETERMINING THE CORRECT DOSE OF ANTIRETROVIRAL DRUGS

In many countries, the fixed-dose combination tablet of d4T-3TC-NVP will be used. This means that one tablet contains the 3 drugs. There will be two types of tablets, one with 30 mg and the other with 40 mg of d4T plus 150 mg of 3TC and 200 mg of NVP.

**Dosage of antiretroviral drugs used in the first-line ARV regimens**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>zidovudine (ZDV)</td>
<td>300 mg twice daily</td>
</tr>
<tr>
<td>lamivudine (3TC)</td>
<td>150 mg twice daily</td>
</tr>
<tr>
<td>nevirapine (NVP)</td>
<td>200 mg twice daily, except for the first 2 weeks</td>
</tr>
<tr>
<td>efavirenz</td>
<td>600 mg one daily*</td>
</tr>
<tr>
<td>Two doses, depending on weight</td>
<td></td>
</tr>
<tr>
<td>stavudine (d4T)</td>
<td>30 mg twice daily if the patient's weight is less than 60 kg</td>
</tr>
<tr>
<td></td>
<td>40 mg twice daily if the patient's weight is more than 60 kg</td>
</tr>
</tbody>
</table>

* If EFV is given in combination with rifampicin, a higher dose of EFV might be required (800 mg instead of 600 mg). Call for advice.
"Lead-in" (also called "escalating") dose of nevirapine

During the first 2 weeks of antiretroviral therapy, nevirapine is used in a lower dose. We call this the 'lead-in dose'. Instead of giving 200 mg twice daily, we give 200 mg once daily for the first 2 weeks. After 2 weeks, the patient should come back and start with the full dose of 200 mg twice daily if there are no complications. This is called an "escalating dose" (the dose goes up). First it is lower for 2 weeks (200 mg once daily) then it escalates (goes up) to 200 mg twice daily. The dose then stays at 200 mg twice daily. This is important to reduce side effects from NVP.

Never start treatment with the full twice daily dose of nevirapine - this can result in a serious rash or liver problems.

Hence, during the first 2 weeks, the patient should take: 1 fixed-dose combination tablet of d4T-3TC-NVP in the morning, and in the evening 1 tablet of d4T and 1 tablet of 3TC (these are separate tablets, not the fixed-dose combination tablet).

After the first 2 weeks, the patient takes 1 fixed-dose combination tablet in the morning and one fixed-dose combination tablet in the evening.

For the first 2 weeks of treatment, the patient should receive 14 fixed-dose combination tablets (d4T-3TC-NVP in one), 14 tablets of d4T, and 14 tablets of 3TC.

EXERCISE 10-1

A patient Emma is starting on d4T-3TC-NVP. You have the drugs in separate tablets and a combined tablet (fixed-dose combination).

Write out the full names of the 3 drugs.

______________________________
______________________________
______________________________

What is the common name for the combined tablet used in your area?

______________________________

Emma weighs 50 kg and is just starting on . What instructions should you give her for the first two weeks on how to take the drugs (we will learn about the side effects counselling later)?

What instructions should you give Emma after 2 weeks if she has no problems taking the drugs?
**EXERCISE 10-2**

Your facilitator will give you:

- 14 FDC tablets with d4T-3TC-NVP
- 14 tablets d4T
- 14 tablets 3TC

Show your fellow participant how to take these morning and night at the start of ART. Lay them out on the table.

**EXERCISE 10-3**

What is the dose of stavudine (d4T) in:

- A small adolescent ________________?
- A wasted adult weighing 50 kg ________________?
- This adult now weighs 62 kg ________________?

What should you do if a patient who is on d4T-3TC-NVP for 12 months gains weight from 55 kg to 61 kg? What instructions would you give? How would you write it on the HIV Care/ART card?
Learning objectives

By the end of this chapter you should be able to:

- describe the most common side effects for each ARV drug used in the first-line ARV regimens;
- explain the 3 different categories of side effects;
- explain the most important side effects to patients;
- explain to the patients what to do if side effects occur;
- understand the possible explanations when new signs and symptoms develop in a patient taking ART:
- manage simple side effects;
- list which side effects need advice or referral.

Maria takes the ART as prescribed. She has mild nausea, but the nurse warned her about that. The nurse told her it was normal, and that it would disappear after some weeks. Since Maria has been informed about this, she does not worry too much. She eats frequent small meals of her preferred food, and continues the treatment.
Kato takes the ART as prescribed. He has nightmares, but the nurse warned him about that. The nurse told him it was normal, and that it would disappear after some weeks. Since Kato has been informed about this, he does not worry too much. He tries to do a pleasant activity before going to sleep. After some weeks, the nightmares disappear, as the nurse has told him.

3 weeks after starting ART, Mr. Richard has a mild dry rash on the trunk. It is itching, but he has no fever. What would you do? What could be the cause of this?

The nurse gave him chlorpheniramine and continued the ART, and warned Mr. Richard to return if the rash worsened or if fever developed. The rash disappeared after some days. The nurse had also warned Mr. Richard about some other side effects of the drugs, but so far, he did not suffer any. What are the side effects you should mention to Mr. Richard?

**INTRODUCTION TO SIDE EFFECTS**

Most drugs have side-effects of some sorts, although in the majority of cases they are mild, and not all people taking drugs will experience the same effects and to the same extent. **Less than 5% of patients taking ART will have serious clinical side effects.** Many more will have non-serious but annoying side effects, especially in the beginning of therapy.

Risk of side effects can be a big worry for your patient when they start ART for the first time. It is important that you warn patients about the very common side effects and suggest ways that they can be managed by the patient. It will help if you tell them what they can expect. You should also make it easy to get advice on managing other side effects or any worries they have.

People with a higher number of side effects will usually stop taking their drugs correctly because they are discouraged by the side effects. If people do not take their drugs well, the therapy will not be successful.

So if people are complaining about side effects, you should take their complaints seriously; if not, they might start to 'forget' taking pills.
THREE TYPES OF SIDE EFFECTS

THE FIRST TYPE: SIDE EFFECTS THAT ARE UNCOMFORTABLE FOR PATIENT, BUT NOT DANGEROUS.

(a) Some side effects are very common. Because they are very common, it is important to warn the patient about them and give them some simple advice on what to do if they occur.

- They include symptoms such as nausea, headache, dizziness, diarrhoea, feeling tired and muscle pain.
- Usually they occur when treatment begins and then improve within 2 to 4 weeks.
- If the patient does not understand these side effects and does not have a plan of how to cope with them, adherence will be poor then HIV resistance will occur and treatment outcome will not be good.
- Efavirenz has some typical side effects that occur frequently. The patient should be reassured that this will go away after some weeks. For example: efavirenz can cause strange dreams and nightmares, mood changes, dizziness and loss of concentration.

The list of possible side effects which are not dangerous is long—telling the patient about all of them could be discouraging and confusing. For each drug (and each drug regimen), we need to learn what the very common side effects are that we should prepare the patient to deal with. We also need to know how to provide clinical management when the patient seeks care, because the symptoms persist or become severe.

Sometimes even these common side effects can be more severe if they persist for a long time or if the patient has an especially severe reaction. It should be made clear to the patient that after trying home management of the symptoms, that if the symptoms persist or become worse, the patient should seek care.

(b) Less common side effects

It is not necessary (or advisable) to warn patients about these side effects. However, you should be able to manage them. These include blue nails (from ZDV) or side effects that are very common with certain drugs but uncommon but do occur with the other drugs.
SECOND TYPE: POTENTIALLY SERIOUS SIDE EFFECTS

These require emergency consultation. The patient needs to be warned about these. For some, the patients need to seek care urgently if they occur. These are marked with a drum on the Patient Treatment Card.

Examples:

- Pallor (anaemia—can occur with ZDV)
- Yellow eyes due to sick liver (hepatitis—can occur with NVP or EFV)
- Severe abdominal pain
- Rash. Although many new rashes that occur on NVP or EFV are mild, they can be serious so it is important for the patient to show them to the health worker as soon as possible.
- Burning, numbness or tingling in hands and feet due to d4T (= peripheral neuropathy). In this case, the patient may not need to seek care immediately but should tell a health worker at the next appointment.

THIRD TYPE: SIDE EFFECTS OCCURRING LATER DURING TREATMENT

They tend to occur after the patient has been taking ART for several months or even years.

The most common one is an abnormal distribution of body fat: fat gain on the abdomen, breasts, shoulders, neck (sometimes with fat lumps under the skin), as well as fat loss from legs, arms, buttocks and face (lipodystrophy).

Good management of side effects includes:

- Discuss very common possible side effects before the person starts the medication
- Give advice on how to manage these side effects. Use the Patient Treatment Card for the regimen.
- Warn patients about potentially serious side effects and tell them to seek care urgently if they occur.
- Give immediate attention to side effects: access to the clinic or by phone
- Initiate a discussion about side effects, even if the patient does not mention them spontaneously
- Refer the patient to peer-educators.
### Very common side-effects:
warn patients and suggest ways patients can manage; also be prepared to manage when patients seek care

<table>
<thead>
<tr>
<th>Drug</th>
<th>Side Effects</th>
<th>Potentially serious side effects: warn patients and tell them to seek care</th>
<th>Side effects occurring later during treatment: discuss with patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>d4T stavudine</td>
<td>Nausea, Diarrhoea</td>
<td>Seek care urgently: Severe abdominal pain Fatigue AND shortness of breath</td>
<td>Changes in fat distribution: Arms, legs, buttocks, cheeks become THIN Breasts, belly, back of neck become FAT</td>
</tr>
<tr>
<td>3TC lamivudine</td>
<td>Nausea, Diarrhoea</td>
<td>Seek advice soon: Tingling, numb or painful feet or legs or hands</td>
<td></td>
</tr>
<tr>
<td>NVP nevirapine</td>
<td>Nausea, Diarrhoea</td>
<td>Seek care urgently: Yellow eyes Skin rash Fatigue AND shortness of breath Fever</td>
<td></td>
</tr>
<tr>
<td>ZDV zidovudine (also known as AZT)</td>
<td>Nausea, Diarrhoea, Headache, Fatigue, Muscle pain</td>
<td>Seek care urgently: Pallor (anaemia)</td>
<td></td>
</tr>
<tr>
<td>EFV efavirenz</td>
<td>Nausea, Diarrhoea, Strange dreams, Difficulty sleeping, Memory problems, Headache, Dizziness</td>
<td>Seek care urgently: Yellow eyes Psychosis or confusion Skin rash</td>
<td></td>
</tr>
</tbody>
</table>

### A key message:

For all combination treatments, it is important to advise patients about the regimen as a whole and not on each specific drug. They should never stop just one drug or take a lower dose. If a patient thinks he has a side effect from one drug, which is so bad that he wants to stop or change the treatment, he should go as soon as possible to the clinic. Consult with the clinician or, if not available, STOP ALL THREE DRUGS. Never just stop one or two drugs.
Responding to new symptoms or signs in an HIV patient on ART means considering more possibilities than in an HIV patient before starting ART. As we learned in Chapter 5, new signs and symptoms can have several explanations. When a patient is on ART, several additional possible explanations are added:

Possible causes for signs and symptoms

<table>
<thead>
<tr>
<th>HIV positive or negative patient</th>
<th>HIV+ patient with immunosuppression, before ART</th>
<th>HIV+ patient on ART</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Immune reconstitution syndrome (IRIS)</td>
<td>ART side effects</td>
</tr>
<tr>
<td>Opportunistic infections</td>
<td></td>
<td>Opportunistic infections</td>
</tr>
<tr>
<td></td>
<td>Opportunistic infections</td>
<td>From failure of therapy</td>
</tr>
<tr>
<td>Common infections and other acute and chronic problems (not related to HIV)</td>
<td>Common infections and other acute and chronic problems (not related to HIV)</td>
<td>Other (for example, CD4 still not high enough to protect the patient)</td>
</tr>
</tbody>
</table>

What are the new possibilities that need to be considered?

- **Side effects**
- **Opportunistic infections**: These can still occur in patients on ART. In the first months after starting ART, the CD4 count may not have gone up high enough yet to protect against infection. Later in treatment, a new opportunistic infection may be a sign of failure of therapy. This means the ART has stopped being effective, because the virus made some changes in its structure or that the patients have not taken the drugs correctly with good adherence.
Immune reconstitution syndrome (also called Immune Reconstitution Inflammatory Syndrome or IRIS): Immune reconstitution syndrome is a strong reaction of the body's defence (becoming strong again due to ART) against a previously "quiet" opportunistic infection. In many cases, the symptoms of the immune reconstitution syndrome will be similar to the symptoms of a normal opportunistic infection. In some cases, the symptoms of an opportunistic infection in the framework of an immune reconstitution syndrome will be different from the classical symptoms of the opportunistic infection. This assessment will help you to detect all this.

IMMUNE RECONSTITUTION SYNDROME

We mentioned above that when monitoring patients starting ART, we should not confuse therapy failure with immune reconstitution syndrome. This is the topic of this chapter.

FIRST STEP IN UNDERSTANDING IMMUNE RECONSTITUTION SYNDROME: UNDERSTAND DISEASE IN HIV NEGATIVE PEOPLE

Our body usually presents with symptoms of disease when there is a kind of 'battle' going on between the micro-organisms causing the disease and the body's 'soldiers' (the immune system).

Comparison:

*Imagine a small house.*

*Now, a thief enters the house to steal. If the people are awake and strong, maybe the owner of the house can take a stick to hit the thief. He might even fight with the thief. During this fight, some things in the house may be damaged accidentally.*

*Conclusion: the owner has defended his property and prevented the thief from stealing, but the cost of it is that the house is a little bit damaged due to the fight.*

→ The same is true for our body: we defend our body against diseases, but the body suffers temporarily from some symptoms due to the fight between the body's defence and the disease.

SECOND STEP IN UNDERSTANDING IMMUNE RECONSTITUTION SYNDROME: UNDERSTAND DISEASE IN PEOPLE WITH AIDS

As we mentioned in the beginning of this course, patients with advanced HIV/AIDS have a seriously damaged immune system. There are almost no CD4 left to fight diseases.

In case of HIV/AIDS, diseases can enter the body easily, because the defence is weak. However, there are still some 'soldiers' left, and they will do a battle or fight with the disease. The person will have symptoms of an opportunistic infection.

But, AIDS can be so advanced that there are no 'soldiers' left.
In that case, an opportunistic disease can enter the body and there will be no battle or fight.

No battle means: no typical symptoms.

This means that the person has an opportunistic disease, but does not present with the typical symptoms.

Comparison:

*Think again of the thief in the house.*
*Imagine now that the owner is very old, deaf and cannot get out of bed easily.*
*There will be no fight with the thief, because the owner is too weak. So, there will be no damage in the house due to fighting.*
*But the thief will do harm and steal things, without somebody noticing.*

→ This is the way OI are present in very advanced AIDS: they do harm, but it is hard to notice, because there is no defence anymore. The OI is ‘quiet’.

**THIRD STEP IN UNDERSTANDING IMMUNE RECONSTITUTION SYNDROME:**
UNDERSTAND WHAT HAPPENS WHEN WE START ART IN PEOPLE WITH A ‘QUIET’ OI

When a person with a disease in the body without knowing it (because there are no typical symptoms due to the extremely poor defence) starts to take ART, strange things may happen.

The ART will make the body’s defence stronger. When the immune system becomes stronger, the body will start to fight with the disease that was already present there. This will cause sudden symptoms and the patient may feel very sick.

This is called an immune reconstitution syndrome.

Although the patient feels sick, it is a sign that the body defence starts to work again, and it does not mean that the ART is bad. This immune reconstitution syndrome can present in different ways, and require a different management.

If not recognized, some cases may be fatal.

This is why we should always call for advice or refer patients who are on ART and who have new symptoms (like fever or cough or headache). New symptoms shortly after the start of ART are often not due to failure of therapy, but due to immune reconstitution Syndrome or drug side effects.

Typical manifestations of immune reconstitution syndrome are Herpes Zoster or tuberculosis occurring shortly after the initiation of ART.

Side effects of ART, opportunistic infections from failure of therapy and other OIs, and immune reconstitution syndrome are very important to recognise. If they are not recognised, they can be fatal in some cases. Side effects, treatment failure and immune reconstitution syndrome each require a specific management, often with advice from a doctor or medical officer.
Let us now consider each sign or symptom, consider what could be the cause, and how to manage the problem. For simple side effects, you can use the Palliative Care module and section 8.12 in the Chronic HIV Care module to manage side effects.

**Cough or difficult breathing on ART**
Difficult breathing in a patient on ART could be immune reconstitution or a serious drug toxicity. The patient needs referral.

A frequent cause of cough, often together with fever and/or night sweats, shortly after starting ART, is pulmonary TB unmasked by immune reconstitution syndrome. Due to a strong reaction of the body's defence, symptoms of TB can suddenly appear, due to a 'battle' between the now recovering body defence and the TB bacilli. TB immune reconstitution often occurs in the first 6 weeks after initiation of ART. This does not mean the ART is not working.

The management of TB unmasked by immune reconstitution syndrome needs advice from a doctor or medical officer.

When a patient develops a persistent cough after many months or years of therapy, it might mean that the patient's defence is becoming weak again, because the therapy is no longer working.

If the patient develops difficulty breathing, it might also be a side effect of certain antiretroviral drugs. This needs advice from a doctor.

**Fever on ART**
Fever can be due to immune reconstitution syndrome (within 2-3 months after starting ART) or due to opportunistic infections returning due to treatment failure (a long time after starting ART, often in a patient who did not take the pills very well, or a side effect of the medication, or a non-HIV related problem. A patient with fever needs further investigation.

Patients taking nevirapine can have fever as a side effect, with or without a skin rash. Other drugs can cause fever as well.

It is often not possible to differentiate the cause of the fever in the health centre. First we need assess further with the Acute Care guidelines, to look for apparent causes of fever, and when necessary call for advice or refer.

**Night sweats**
These can also be due to immune reconstitution syndrome (usually within 2-3 months after starting ART) or due to opportunistic infections from treatment failure.

**Herpes simplex infection**
If these persist for more than a month or are extensive, the patient has a new stage 4 sign. In a patient taking ART for months or years, this may mean the therapy does not work. Call for advice.

It is not uncommon that herpes simplex lesions worsen shortly after initiation of ART, due to immune reconstitution syndrome.
Diarrhoea

Diarrhoea is a frequent side effect of ART, and it occurs shortly after initiation of ART. Usually, it is self-limiting and gets better after some weeks.

If diarrhoea appears a long time after initiation of therapy and becomes chronic, it might be a new OI. A new OI appearing in a patient taking ART may mean the therapy does not work anymore. In that case, you should call for advice.

<table>
<thead>
<tr>
<th>Manage diarrhoea</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication/clinical</td>
</tr>
<tr>
<td>➤ Manage as in <em>Acute Care</em> module (check for dehydration, blood in stool, persistent diarrhoea).</td>
</tr>
<tr>
<td>➤ To prevent dehydration:</td>
</tr>
<tr>
<td>➤ Drink extra fluids frequently—see plan A for adults (<em>Acute Care</em> module)</td>
</tr>
<tr>
<td>Use ORS if large volume diarrhoea or persistent diarrhoea</td>
</tr>
<tr>
<td>➤ Advise to continue eating</td>
</tr>
<tr>
<td>➤ Give constipating drug unless blood in stool or fever or child less than 5 or elderly:</td>
</tr>
<tr>
<td>➤ oral morphine 2.5-5mg every 4 hours (if severe)</td>
</tr>
<tr>
<td>➤ codeine 10mg 3 times daily (up to 60 mg every 4 hours) or</td>
</tr>
<tr>
<td>➤ loperamide 4mg once, then 2mg per loose stool to maximum 16mg/day</td>
</tr>
<tr>
<td>➤ if patient becomes even weaker, or</td>
</tr>
<tr>
<td>➤ if broken skin around the rectal area</td>
</tr>
</tbody>
</table>

Headache

Headache can be a drug side effect, especially when the patient is taking ZDV or EFV. Is usually gets better after the first weeks of therapy. If it doesn't, you should suspect something else such as meningitis. See the *Acute Care* module, page 47)

Meningitis can present in the framework of an immune reconstitution syndrome and needs prompt treatment; call for advice.

Headache in a patient who is taking ART for a long time can be a manifestation of meningitis due to failure of therapy.

Persistent headache, continuing after the first weeks of ART, or new headache during ART need further advice.
Nausea or vomiting
These are common side effects in the first weeks of ART for all the drugs. Make sure the patients are taking the ARV drugs with food. Use page P23 of the Palliative Care module for advice on managing nausea or vomiting. These can both be associated with mild abdominal pain.

<table>
<thead>
<tr>
<th>Control nausea and vomiting</th>
</tr>
</thead>
<tbody>
<tr>
<td>❖ Give antiemetic: metoclopramide (10mg every 8 hours, give only for a day at a time) or haloperidol (1-2mg once daily) or chlorpromazine (25-50mg every 6-12 hours)</td>
</tr>
<tr>
<td>❖ If the sick persons feel like vomiting:</td>
</tr>
<tr>
<td>❖ Seek locally available foods which patient likes (tastes may change with illness) and which cause less nausea</td>
</tr>
<tr>
<td>❖ Frequently offer small foods such as roasted potatoes, cassava or ___________</td>
</tr>
<tr>
<td>❖ Offer the drinks the sick person likes, such as water, juice or tea; ginger drinks can help</td>
</tr>
<tr>
<td>❖ Take drinks slowly and more frequently</td>
</tr>
<tr>
<td>❖ Avoid cooking close to the sick person</td>
</tr>
<tr>
<td>❖ Use effective and safe local remedies (example: licking ash from wood, ___________ )</td>
</tr>
</tbody>
</table>

Seek help from trained health worker for vomiting more than one day, or dry tongue, or passing little urine or abdominal pain.

In case of severe or worsening vomiting, you should call for advice and make sure the patient stays hydrated. Persistent vomiting can lead to serious medical problems such as dehydration and chemical imbalances. Give antiemetic medicine as needed.

Fatigue or feeling tired
This side effect usually gets better within the first weeks of treatment although it can last as long as 4 to 6 weeks with zidovudine.

When fatigue is severe or associated with difficulty breathing or pallor, it can be serious - seek care urgently. This may indicate lactic acidosis, sepsis or another serious problem.

Yellow whites of the eyes
Nevirapine is known to cause a sick liver (hepatitis), but is can also happen with efavirenz, and certain TB drugs.

This is due to hepatitis which is associated with both nevirapine (most commonly) and efavirenz. There may also be other hepatitis symptoms including yellow skin, belly pain with nausea or vomiting, and feeling tired. This is caused by liver damage due to the drugs.

Stop ALL ARV drugs (not just NVP or EFV!). The patient needs a liver function test (ALT test). You should call for advice or refer the patient.
Tingling, weakness, numbness or burning in hands or feet
This is due to damage of the nerves called peripheral neuropathy. Certain antiretroviral drugs can cause nerve damage, especially d4T. The risk of developing this side effect increases when it is given together with INH.

Usually, this side effect worsens gradually over time. If this side effect becomes serious and is ignored by the health care worker, irreversible nerve damage can occur. That is why the health care worker should call for advice in case of neuropathy.

Patients on d4T-3TC-NVP should have the d4T discontinued. Zidovudine can be substituted if there is no severe anaemia (check haemoglobin). Consult with the medical officer on this.

**Painful muscles**
ZDV often causes painful muscles occur mostly in the beginning of treatment. It gets better after some weeks.

**Headache**
Problems of headache usually get better after some weeks. It is common in the first weeks with both ZDV and EFV. If it persists or is severe, see earlier discussion in this chapter—this may be meningitis related to immune reconstitution syndrome or failure of therapy.

For relief, suggest resting in a quiet, dark room with eyes closes. Place cold washcloths over the eyes. Massage the base of your skull with your thumbs and massage both temples gently.

Avoid or limit foods that seem to trigger the headaches. This is individual and can include alcohol, caffeine-containing drinks, and monosodium glutamate, or onions.

**Pallor (anaemia)**
Some patients can suddenly develop an anaemia due to ZDV. This is a serious side effect requiring advice from a doctor. The patient can complain of pallor of the palms or the conjunctivae, or of shortness of breath or fatigue. Feeling a little tired is common in the beginning of treatment and should not worry the patient.

Obtain a haemoglobin if possible and stop the drug and call for advice or refer.

**Difficulty sleeping**
This problem usually resolves spontaneously after the first weeks of treatment. It is common with efavirenz.

**Changes in fat distribution (also called lipodystrophy or lipo-atrophy)**
- Fat gain on the belly, breasts, shoulders, neck (sometimes with fat lumps under the skin)
- Fat loss from legs, arms, buttocks and face

This side effect gets worse gradually. It is not dangerous, but it can discourage the patient to take the pills, and thus it is serious. Look at photos.
**Skin rash**
A number of patients will develop a rash of the skin in nevirapine (NVP) or efavirenz (EFV). There are different types of rash:

- Dry rash: macula (pink spots), papules, dry desquamation—look at photo.
- Wet rash: vesicles (small blisters), ulcerations, wet desquamation, involvement of eyes or mouth. This is a dangerous side effect.
- Dry or wet rash with fever. This is a dangerous side effect.

In case of rash, it is good to call for advice. A dry rash without fever is usually not very dangerous but it is important to be sure.

**Abdominal pain may occur with d4T from pancreatitis**
This side effect is serious and can present with abdominal pain, sometimes with vomiting. The patient should be referred.

**Efavirenz can cause many central nervous system (brain) problems**

- Difficulty sleeping
- Strange dreams and nightmares
- Loss of concentration or memory
- Getting more worried or upset than usual
- Feeling depressed
- Mood changes
- Dizziness
- Avoid social contact
- Become worried to go outside

These side effects are very frequent, and will occur to some extent to the majority of your patients on a regimen that contains EFV. They are annoying but not dangerous and will get better after the first weeks. Patients should be informed about these side effects in order to cope with them. Advise them that it is best to take the efavirenz tablet in the evening.

If your patient is a driver or operates heavy machinery, warn him or her not to do so if they feel dizzy or cannot concentrate.

Some patients have more severe central nervous system problems and get really depressed or go 'crazy' (psychosis or bizarre thoughts) or get confused. If this happens, they should seek care at once.

It is not always easy to differentiate side effects from new opportunistic infections (due to failure) or from immune reconstitution syndrome.

Annoying but not serious symptoms - for example headache - that get worse AFTER the initial phase of ART, or that do not resolve after the initial phase of ART should make you suspect an OI rather than a side effect. That is why you should always call for advice in these cases.
Look at the Patient Treatment Card for each regimen in Annex D. On these Patient Treatment Cards, the common side effects and advice on when to seek care urgently are combined for the 3 drugs in the regimen. It is not necessary or helpful to explain to the patient what drug causes what problem since this may cause them to stop one drug, which is very bad (leads to resistance) and must be avoided. It is important if the drugs are really not tolerated to stop all drugs at once then decide what to do.

It is not necessary to tell all possible and rare side effects to the patient or spending to much time anticipating possible problems. This might just confuse and discourage the patient unnecessarily. It is important for the patient to know about the very common side effects and what to do and when to seek care urgently for signs that may indicate serious toxicity. That is why the Patient Treatment Card only contains the most important information.

Prevention messages are on the back. It is very important when giving ART advice to emphasize prevention and to make sure that the patient understands that even on ART they must still use condoms and practice safer sex.

**EXERCISE 11-1**

The trainer will distribute a card with a side effect to all of you.

The trainer will draw a table with the five first-line ARV drugs you know on the board.

Now, you will be invited to stick your side effect next to the appropriate drug.

The exercise might be repeated in the end of this chapter.

**EXERCISE 11-2**

You will be invited to participate in a role-play. The same patient will come back for several consultations. For each consultation, another participant will be invited to play the role of the nurse. Make sure you explain well the most important side effects to the patient and advice him what to do in case they occur. Decide what to do when a patient comes to you with a side effect. *Use the Patient Treatment Cards (Annex D).*

1. The patient has a CD4 of 180 cells/mm³ and has been treated successfully for chronic diarrhoea. You decide to start d4T-3TC-NVP. What will you tell the patient?

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________

1. The patient has a CD4 of 180 cells/mm³ and has been treated successfully for chronic diarrhoea. You decide to start d4T-3TC-NVP. What will you tell the patient?
The same patient returns 2 weeks later. He has a dry skin rash, without fever or other symptoms. What will you say, what will you do?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

On the next consultation, the patient complains about numbness in the fingers since 2 weeks. He is still taking d4T-3TC-NVP. What will you say and do? What is the possible cause?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

2. Another patient has been prescribed ZDV-3TC-EFV. What advice will you give him?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

You see the same patient back one month later. The patient has suffered a lot from strange dreams in the beginning, but now he feels OK, he has no problems. What will you tell him?

_____________________________________________________________________
_____________________________________________________________________

Two weeks later, the patient comes to you and says he feels very tired since 4 days. He also has shortness of breath when walking quickly. What could this be? What will you do?

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

EXERCISE 11-3

The patient is taking d4T-3TC-NVP. Write the type of side effect next to each one. Put an asterisk on the ones that require urgent care seeking.

- Yellow eyes
- Changes in fat
- Skin rash
- Nausea, vomiting, diarrhoea
- Abdominal pain
- Tingling or numbness in feet or hands
Chapter 12: Support ART initiation then monitor and support adherence to ART

Learning objectives:

By the end of this chapter you should be able to:

- use a simple pill chart (including pill charts for patients who cannot read);
- give several practical tips to the patient on how to remember to take the drugs;
- understand the importance of constructing a team with other people, to increase your patient's adherence: friends, treatment supporter, home-care teams, support groups;
- recognise barriers to adherence;
- provide solutions for barriers to adherence;
- assess adherence;
- know the limitations of each method of assessment of adherence.

Maria has to come regularly to the health centre. The nurse always asks about adherence. Maria never forgets her drugs. Her partner is also taking treatment, and they help each other to remember to take the drugs.

Kato has to come regularly to the health centre. The nurse always asks about adherence. Kato never forgets his drugs.
Mr. Richard is a very busy man. He needs to travel a lot for the business. Sometimes he is stressed, because he has so many things in his head. From time to time, he forgets the pills, especially when travelling, because he forgets to take them with him, or because he is in a meeting.

What would you do to help Mr. Richard? What would you tell Mr. Richard?

**SUPPORT ART INITIATION—See section 8.9 of the Chronic HIV Care module**

The sections from the module are in bold. Additional explanation has been added in between.

The first time the patient will go home with ART is crucial. You must be sure all information is well understood and that all possible tools to assure adherence are provided.

It is important to explain carefully, using the Patient Treatment Card.

**ASSESS**

See also Chapter 7.

- **Assess the patient’s goals for today's visit**
  "Today we will be starting you on your ART. Is there anything special about HIV/AIDS or ART you would like to address in today's session? Are there any concerns that you have which you would like to discuss?"

- **Check understanding of the information given before—make sure patient understands the illness, treatment, and possible side effects.**
  The patient has been given a large amount of information in preparing for ART. It is important to reassess the patient’s understanding. Remember to use **specific questions** and to **make the patient feel comfortable**. You can say to the patient:

  "I know that we have given you a lot of information about HIV/AIDS and ART. Let me ask you some questions to make sure that there is no confusion or misunderstanding as you start your treatment."

  Here are some specific questions from Chapter 7 that you can ask:
  ✓ What are the benefits of ART?
  ✓ How long do you have to take ART?
  ✓ What is the effect of ART on the body's defence?
  ✓ Why is it important to come regularly to the health centre when you are taking ART?
  ✓ What do you know about side effects of ART?
  ✓ Why is it important not to miss a dose when you take ART?
  ✓ What happens if you do not take ART correctly?
  ✓ Why is it not good to combine ART with other drugs without consulting the health centre staff first?"
Reinforce the information given before.

Advise on details of first-line regimen:
- Explain the purpose of and how to take each pill. Provide and explain card summarizing treatment. Give patient the Patient Treatment Card which corresponds to his/her treatment regimen. You can go through the card together.

Make sure patient understands the importance of adherence.
Remind the patient that ART is lifesaving and that his life depends on taking them every day at the right time. Use his medication regimen and discuss which pills need to be taken at which specific time.

Advise on diet
If the patient will be taking efavirenz, advise him not to take it with a fatty meal. Give examples of what he should avoid just before or after swallowing the pill: fried chicken, fried fish fingers, crisps, and chips.

Explain limits on alcohol and drug use (counsel on low risk drinking or abstinence from alcohol—see Brief Intervention module). These are important for adherence. It is important for the patient to realize that their regimen may not go well with alcohol:
- efavirenz has brain effects which mean that it can make the patient sleepy or dizzy. Drinking alcohol may enhance these effects.
- nevirapine and efavirenz both can be toxic to the liver. Alcohol is toxic to the liver. Taking both alcohol and one of these drugs can add up to cause liver damage. So it is important to reduce drinking alcohol to either very low risk levels or, if possible, to stop. There are materials that can help you counsel the patient on how to reduce or stop alcohol.
- for any medication, high amounts of drinking can be a serious problem because they may cause the patient to forget to take his medication.

Explain side effects.
Warn about both the very common side effects and how to manage them and symptoms that indicate the patient needs to come back urgently. This is covered in Chapter 11.

- Prepare patient and treatment supporter to handle common side effects. Most side effects can be treated symptomatically.

- Explain which side effects are likely to improve with time (related to initiation of treatment) and their likely duration. Again go through the Patient Treatment Card that corresponds to the regimen he is starting. Give him examples of the common side effects such as nausea or diarrhoea which occur often with the first line regimens and what he can do if these side effects occur.

- Explain which are more serious and require urgent return to clinic. Again use his specific Patient Treatment Card to go through the major side effects which can occur on the regimen he is taking.
- Explain that patient can still transmit HIV infection when on ARV therapy. It is very important to still practice safer sex and other practices to prevent transmission (see section 9.5 of the Chronic HIV Care Module). Remind the patient that he or she should still be using condoms with his or her partner to prevent transmitting the infection or to prevent getting re-infected (which can further impair immunity if re-infected with a different strain).

It is important to repeat key information concerning HIV/AIDS and ART.

**AGREE**

- Make sure the patient agrees to the regimen and is a true partner in the treatment plan. Is the patient still ready and willing?

- Make sure patient understands that his/her life depends on taking the medicine every day.

- Agree on plan for support by treatment buddy and support groups. Tell patient that you realize that taking the medications will be difficult and having a treatment buddy and attending the support groups can help him in managing this lifelong commitment. The patient can learn adherence techniques and ask questions from others who are going through the same treatment.

**ASSIST**

- Develop (then reinforce on each visit) a concrete plan for the specific ARV regimen. Come up with a plan for how patient will remember to take the medication before he leaves the clinic with his new ART.

  - When to take; times for every 12 hour dosing; how to make it a habit.
  - Explain escalating dose of nevirapine.
  - How to remember—provide and explain written schedule, pillbox, pill chart and other aids.

  - You can give a pill chart to the patient. Check if the patient understands correctly the information as written on the pill chart by asking the patient to repeat the information.

  - For patients who cannot read, it can be useful to indicate a colour on the pill bag (e.g. colour the bag with ZDV red), and use the same colour on the pill chart. Use the sign of sun and moon to demonstrate morning and evening doses, and draw the adequate quantity of pills instead of writing the number.

Example of pill chart for patients who cannot read:

<table>
<thead>
<tr>
<th>Medication</th>
<th>AM</th>
<th>PM</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZDV 300 mg</td>
<td>🌞</td>
<td>🌙</td>
</tr>
<tr>
<td>3TC 150 mg</td>
<td>🌞</td>
<td>🌙</td>
</tr>
<tr>
<td>EFV 200 mg</td>
<td>🌞</td>
<td>🌙</td>
</tr>
</tbody>
</table>
- If possible, provide a pillbox, so the patient can always check if s/he has missed a dose. Pillboxes are containers for storing medication with dividers for each day and each dose during the day.

- Encourage the patient to use a pill beeper or alarm watch for both morning and evening doses. Beepers should be discrete to help the patient feel that confidentiality is not a risk.

- You can provide a diary. This means the patient has a booklet where he ticks every time he takes the drugs. The disadvantage is that the patient can fill it out without taking the drugs, or that the patient can take the drugs but forget to tick it in the diary.

- Provide psychosocial support (Annexe A.1 of the Chronic HIV Care module). Elicit concerns. Use empathy.

- Encourage patient to join an ART adherence support group. Give him specific information as to where and when they meet.

- Arrange home visit, if feasible. Really knowing your patient’s home situation and helping him or her to make arrangements for adherence at home can be very helpful. The home visit also confirms where the patient lives so that if they fail to come from clinic, they can easily be followed up.

Home visits can be done in collaboration with the community-based organizations providing support for ART.

ARRANGE

- Next follow-up visit in clinic, home visit if feasible, and next visit with district clinician (if required).

- Agree on best way to access help between visits.

- Make sure patient understands where and when s/he will see health worker (see section 10.3 of the Chronic HIV Care Module).

Write it down for patient, if possible. Record what happened during this visit.

By the end of this visit, the health worker should have asked the following questions:

- Have I assessed if the patient is ready for treatment?
- Is the regimen compatible with the patient’s life-style?
- Have I reviewed potential or common and potentially serious side effects and does the patient know what to do?
- Did I make the patient repeat dosing time and instructions?
- Does the patient know how to contact the health care team in case of problems or questions?
- Have I identified adherence barriers and made a plan on how to overcome them, in collaboration with the patient?
- Have I provided adherence education?
- Does the patient know the date of the next consultation?
MONITOR AND SUPPORT ADHERENCE - See section 8.9 “Monitor adherence”

We have learned why it is necessary to take the drugs correctly, and not to miss a dose.

If the patient does not have good adherence, the virus might become resistant to the first regimen and we might have to change the initial ART regimen.

The second line regimen is often more expensive, and sometimes not so easy to take (larger amount of pills). It also often causes more side effects.

If the patient has to change several times to other regimens, it may happen that in the end there are no more possibilities to treat the patient, because the virus became resistant to many types of drugs.

How the drugs are provided may vary between districts or types of clinics. You need to know how to explain either possibility:

- **Fixed-dose combinations** are the easiest for the patient to use. These will be provided when possible.

- If the patient is given 3 separate pills to take twice daily, putting the 3 in a blister pack is helpful. You then need to explain that you take all 3 at once.

ASSESS

Do clinical review (sections 3.1 and 3.2 of the Chronic HIV Care module) and respond to any problems or change in status.

Many methods to assess adherence have been tried, but none of them is perfect.

- **Review the medications with the patient and their treatment supporter.** Determine whether there is an adherence problem.

- **Ask questions in a respectful and non-judgmental way. Ask in a way that makes it easier for the patient to be truthful.**

  An individual’s own report of his/her adherence (called a self-report) generally overestimates adherence. However, it can be more accurate if a good relationship with the provider exists.

  Usually, we ask the patient how many doses he forgot in the last 3 days, week and month, or we ask the most recent recall of a missed dose. However, keep in mind that patients may not be comfortable telling you the truth, and tell you what they think you want to hear rather then what really happened.

  You can use the following introduction:
  “Most people with HIV have many pills to take at different times during the day. Many people find it difficult to always remember when to take the pills. It is important for me to understand how you are really doing with the medicine. Do not worry about telling me if you do not always take the dose. I just need to know what is really happening, not what you think I want to hear….”
Here are examples of other ways to assess adherence:

- “Many patients have trouble taking their medications. What trouble are you having?”
- “Can you tell me when and how you take each pill?”
- “When is it most difficult for you to take the pills?”
- “It is sometimes difficult to take the pills every day and on time. How many have you missed in the last 3 days?”

*Ask to see the patient’s self-monitoring sheet, diary or pill chart.* These may be useful, too. If the patient uses one, ask to look at it.

*Ask about important factors that may interfere with adherence.*

- **Patient may not trust the health care worker, or have communication difficulties:** Try to find out why, and see if there are misunderstandings. Try not to take these things personally, and do not lose your temper.
- **Literacy barriers:** Try to work with colours and pictures or symbols.
- **Mental illness, especially depression or alcohol abuse:** Treat depression, refer if necessary. Counsel to reduce or stop alcohol.
- **Patient may not understand the disease and the treatment:** Repeat the basic information, use visual aids.
- **Other beliefs of the patient may interfere:** Instructions from some traditional healers or religions may make it difficult to accept instructions given by the classical health care worker.
- **Unstable living conditions, poor social support:** Try to refer to social institutions or NGO to resolve these problems, refer to support group.
- **Fear that when taking medications, other people will discover HIV status:** Teach to pack the drugs you need for 1 day in a small bag, and take them in the bathroom if you need to take them when visiting family or during work.
- **Unwillingness to set long-term goals (person thinks only about the fact that NOW he has discomfort from the drugs, cannot see the benefit after many years):** Repeated open discussion with the patient, start therapy only when the patient is ready to accept; do not look only at the medical criteria, do not lose patience.
- **Difficult access to health facility:** Reimbursement of transportation fees if feasible.
- **Other immediate life-needs:** Needs such as housing and food, can be viewed as more pressing than taking the medications regularly, so do not ignore these things and try to find solutions.
- **Barriers associated with the regimen:** Frequency of dosing, number of pills, food requirements/restictions, complexity and storage. Check with doctor how regimen can be adapted.
• **Barriers associated with side-effects:** Individuals, especially those who did not have very severe symptoms of AIDS and who are now suffering side-effects from the ART, are likely to skip doses. Always listen carefully when patients mention side effects, and take it seriously. Call for advice from doctor to see if a change in therapy can be made if side effects are interfering with adherence.

- **Ask about stigma related to taking pills.**

- **Count pills.**
  The provider can count the pills at the appointment to see how many doses are missed.

**Disadvantages:**
- Patient who can calculate can throw away some pills before coming to the consultation
- Provider is perceived as a ‘police’ instead of a helper
- Cannot discover if patient is sharing the drugs with other family members
- Cannot detect if pills are taken at the right times

Estimate adherence based on # drugs missed in a certain period. For example, if you dispensed 60 pills at the last visit and the patient missed 3 doses, you can calculate (3/60) X 100 as percent adherence. So the patient missed 5%. In other words, you can write on the treatment card that he was 95% adherent. If he missed 0 doses, then he was 100% adherent. Look at the following example of an adherence table which could be used to help in determining adherence:

<table>
<thead>
<tr>
<th>Missed pills out of 60 pill supply</th>
<th>% Missed</th>
<th>% Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2%</td>
<td>98%</td>
</tr>
<tr>
<td>2</td>
<td>3%</td>
<td>97%</td>
</tr>
<tr>
<td>3</td>
<td>5%</td>
<td>95%</td>
</tr>
<tr>
<td>4</td>
<td>7%</td>
<td>93%</td>
</tr>
<tr>
<td>5</td>
<td>8%</td>
<td>92%</td>
</tr>
<tr>
<td>6</td>
<td>10%</td>
<td>90%</td>
</tr>
<tr>
<td>7</td>
<td>12%</td>
<td>88%</td>
</tr>
<tr>
<td>8</td>
<td>13%</td>
<td>87%</td>
</tr>
<tr>
<td>9</td>
<td>15%</td>
<td>85%</td>
</tr>
<tr>
<td>10</td>
<td>17%</td>
<td>83%</td>
</tr>
<tr>
<td>15</td>
<td>25%</td>
<td>75%</td>
</tr>
<tr>
<td>20</td>
<td>33%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Use your best judgment to estimate the percentage of doses the patients takes, as directed. Write your estimates of the patient’s adherence in taking ARV drugs (and cotrimoxazole prophylaxis) in the ARV drugs column of the HIV Care/ART card. Either record the percentage or write G, F or P:

- **G (GOOD)** equal to or greater than 95% adherence
- **F (FAIR)** 85-94% adherence
- **P (POOR)** less than 85% adherence

Fair or poor adherence requires adherence counselling by a lay provider or health worker (section 8.10 of the *Chronic HIV Care Module*).
How many pills forgotten yesterday, last 3 days, and last month?  
It is often difficult for the patient to remember or estimate the real number of pills that were forgotten. Asking the number of pills forgotten in the last 3 days makes it easier for the patient to recall forgotten doses.

If poor adherence, determine what the problem is:

- Side effects?
- Simply forgot?
- Ran out of pills?
- Which dose missed: morning or evening? Why?
- Cost?
- Reminds you of HIV?
- Misunderstood? (explain, use aids)
- Changed work situation or lifestyle?
- Not comfortable taking medication around others?
- Stigma?
- Different timing when away from home for holiday, travel, weekend?
- Seldom at home and disorganized?
- Problem with diet (food availability)?
- Another medical problem?
- Screen for excess alcohol use and depression and if present, treat.

Other indications of poor adherence are CLINICAL and BIOLOGICAL:
Clinical indications of poor adherence include return of opportunistic infections and weight loss. Biological indications of poor adherence include the CD4 count going down (or viral load going up, if this test is available—it is not necessary at the district level). These can only detect adherence over many months. However, it may be helpful for the patient to know that their adherence to medication can be checked by a blood test.

ADVISE

- Reinforce the information given before.  
  Re-educate about ART and HIV/AIDS if you see that there is some confusion.

- Give additional information that may help with adherence problem.  
  Explain any misconceptions the patient may have.

- Advise on any suggested changes in the regimen (after consulting with clinician. Usually side effects require only changing one drug, not stopping—consult with a doctor or medical officer if this is necessary).

AGREE

- Agree on any changes in Treatment Plan and solutions to adherence problems (if present).

- Discuss the agreements you have reached and check for their commitment.
Provide adherence support.
It is important to learn from previous difficulties or mistakes: discuss problems that occurred in adherence (not just ART, but also prophylaxis) and develop strategies to overcome them in the future.

Reinforce interventions which match the patient's needs and adherence problems, if present:
- Suggest that patients take extra drugs with him/her if s/he goes away for a few days.
- Propose to keep a small supply of drugs where s/he may need them in an emergency—in the car, at work or at a friend's.

Make sure the patient has:
- Plan to link taking medications with daily events such as meals.
- Any device or skill that he or she needs: Look back at page 4 of this chapter for details.

Make sure the patient has the support he or she needs
- Get help from treatment supporter, other family and friends or peers.
  - Encourage the patient to get friends to help him/her remember difficult dose times or when s/he goes out at night.

- Help patient and treatment supporter to find solutions.
  - Make sure your patient knows how s/he can contact the clinic if s/he has difficulties taking the drugs
  - Propose to arrange an appointment with someone who is already taking the same treatment (e.g. support group)
  - Home visits might provide information about the living conditions of the patient, which might be helpful for the staff from the clinic to know. Home visits may sometimes encourage the patient.
  - A ‘buddy’ helps support the person in adhering to his/her regimen by providing emotional support and helping the person by reminding them when to take the medication. The ‘buddy’ can be a friend or family member, HIV infected or not, and can also go to the consultation together with the patient. Remember to record their name on the HIV Care/ART treatment card.
¢ If adherence problem:
  • Get help! Call for advice or refer back sooner but do not “just refer.”
  • Link with home-based care for help and home visits.
  • Seek help from district clinic adherence staff if regimen is too complicated or not tolerated or low adherence.

¢ If repeated missed doses, use special interventions (home visit, etc).
  Remind the patient:

  ✓ THE DRUGS HAVE TO BE TAKEN EVERY DAY AT THE SAME TIME!
  ✓ If a drug has to be taken 2 times per day, there should be a 12 hour interval between the 2 doses. For example, it is not good if you take the morning dose at 6.00 and the evening dose at 21.00, because the interval is more than 12 hours, and the concentration of drug in your body will be too low for several hours, which can create resistance.
  ✓ If you forget, take the dose within 5 hours. After that, wait until the next dose.

ARRANGE

¢ Record adherence estimate on patient’s card.
¢ Arrange for refills.
¢ Arrange for next follow-up visits:
  • In clinic
  • Home visits
¢ Make sure that the patient and supporter understand the follow-up plan and how to contact the clinic team if there is a problem.
**SOME TIPS AND TOOLS TO HELP YOUR PATIENT**

**Storage of the drugs:**
Drugs have to be stored in a cool, dry place, where children cannot reach them.

**Safer sex:**
The patient may feel better when he or she has been on ART for a while, but the virus cannot be eradicated from the body. This is why it is important to still practice safe sex with a condom.

**About treatment:**
Only motivated patients who understand the treatment should be treated.

- Only motivated health care workers who have been trained to use ART should treat.
- Patients need to be monitored regularly.
- Patients must be able to continue ART. If there is only a supply or budget for a few weeks of treatment, it does not make sense to start.
- If several members of the same family are sick with AIDS, all efforts should be made to treat all members of the family, in order to avoid sharing drugs.

**SOMETHING TO THINK ABOUT...**
Some of the patients who are now feeling very well under ART, were previously so sick that their only thought was how to survive, or how to arrange things for when they were dead.

*When these patients are healthy again, certain questions may arise and bring emotional problems even though the patient’s health is good. For example: What about starting a new relationship, what about having children… These are issues that every health worker should*
Chapter 13: Integrate prevention with treatment

Learning objectives

By the end of this chapter you should be able to:

- list the different ways of getting infected with HIV;
- explain and demonstrate the most common ways of preventing HIV transmission through sexual contact;
- learn to efficiently counsel the patient on prevention during every treatment encounter, using a flipchart or the patient treatment card (backside).

Kato would like to get married in the future. The nurse counsels him to use a condom if he has a new partner. He says it is very difficult to do so. The nurse listens carefully to the worries of Kato and understands them. She refers him to a support group, to discuss with others with similar problems.

When Mr. Richard travels, he often has a partner for just one night.

What would you tell Mr. Richard?

The nurse tells Mr. Richard to use a condom, not just to protect the woman from getting infected, but also to protect himself from getting infected with other sexually transmitted diseases, or with a resistant HIV.
A STORY TO MAKE YOU THINK…

Read this story carefully- the trainer can tell you more when you attend the IMAI course. You find a summary of the story below, so you can tell the story to your family, friends and colleagues when talking about HIV/AIDS.

Try to find as much information about HIV/AIDS as possible in this story.

You can write down your ideas in the section that follows the summary of the story.

The story of Flavia and Julio

- The story starts in 1993
- Flavia is a beautiful girl living in the city of Tete
- She just finished university and will get married to Julio
- The family of Flavia really likes Julio

Julio, one year ago

- Julio owns a shop in Tete
- Last year, he went on a business trip
- During this trip, one night, he drunk a couple of beers, and met a sweet lady in the bar
- He spent the night with her

Julio

- Julio does not know it, but during that night, he got infected with HIV

March 1993

- Flavia and Julio get married
- There is a beautiful party, with a lot of people invited and good food
- Flavia and Julio now live together and both work in the business

April 1993

- One day, Flavia feels sick
- It is not very serious, it looks like the flu, with a sore throat and fever
- After some days, she feels better and starts to work again

Flavia got infected

- Flavia does not know it, Julio also does not know it, but Julio now transmitted the virus to his wife
Beginning of 1994

- Flavia is pregnant
- She is very happy
- The first child of the family is born, a little boy
- Joaquim is not infected by HIV

1995, Mateo is born

- The family feels very happy, the business is going well, and Flavia gives birth to another baby, Mateo
- Mateo received the HIV from his mother, and now is infected with HIV as well

1996, Mateo

- Flavia starts to worry: Mateo has fever, diarrhoea, and does not gain weight
- She goes to the doctor.

The doctor talks about HIV/AIDS

- The doctor says that the baby has probably AIDS
- The doctor wants to do an HIV test for Flavia, but she does not accept
- She returns home and does not talk about this with anyone

End of the year 1996

- One night, Mateo dies
- The whole family is very sad

1999, Julio dies

- The last months have been very hard for Flavia
- Julio was often in a very bad mood due to the disease
- She also had to manage the business alone, and take care for her sick husband

Julio, 1997

- Julio starts to be sick very often
- Flavia goes to buy different treatments
- After a treatment, he gets a bit better, but then relapses

Flavia thinks…

- Flavia feels very depressed
- She does not feel sick yet, but she understands now that this terrible disease came into her family
- She is afraid for herself and her child, what will happen to Joaquim if she dies???
QUESTIONS

How and by whom was Julio infected with HIV?
______________________________________________________________

How and by whom was Flavia infected with HIV?
______________________________________________________________

How and by whom was Mateo infected with HIV?
______________________________________________________________

Do you think Mateo died of AIDS?
______________________________________________________________

Why didn't Joaquim get HIV?
______________________________________________________________

How much time was there between the infection of Julio and the year he started to have serious symptoms?
______________________________________________________________

How much time had passed between the time Julio got infected and the time he died?
______________________________________________________________

Why was Flavia sick shortly after marriage?
______________________________________________________________

Linking ART with increased prevention

Providing ART requires integration of preventive interventions into care and treatment. Access to ART can reduce the fear, stigma and discrimination that surrounds HIV/AIDS. This has been shown in projects in Africa, the Caribbean and elsewhere. Being able to provide ART should make it easier to talk with patients about HIV infection, how it is spread, and how they can prevent transmission. Providing ART requires also providing more prevention during your clinical encounters, not less!

Access to ART should also increase the use of HIV testing and counselling. It is very important that you advise patients to be tested and work with HIV+ patients to have their partners and family tested and to educate and counsel them before and after testing.

With appropriate health workers and community efforts to educate and support preventive interventions, ART can help people change behaviours to avoid further transmission. This is important because without these efforts, it is possible that ART could actually lead to myths about a weaker virus or that safer sex is no longer needed amongst patient on ART; this could lead to an increase in risky behaviour and more, not less, transmission. So we need to be active in our prevention efforts when we introduce ART.

Think of ways that your health facility can be involved in new projects that reach out to those most affected by HIV and help provide both prevention, care and (when needed) ART. This is a key time for health workers to provide better
information and more effective education and counselling in order to be sure that we get the prevention benefits from introducing ART.

Access to treatment presents challenges and opportunities for prevention. Inaccurate and unrealistic ideas about the benefits of ART must not be allowed to undermine prevention efforts. Better information and counselling are needed to ensure that the benefits of ART for prevention—reducing stigma and increasing demand for testing and counselling—are not lost. These messages are an integral part of any ART programme.

Although ART can reduce the level of HIV virus, it does not eliminate the virus and transmission can still occur. Patients on ART need to understand that risk remains and they need to work even harder to prevent transmission. This should be part of the agreement in deciding to take ART.

- **Risk of the patient being re-infected with another strain of the HIV virus.**
  Even though they are already infected, they can be infected a second time with a different strain that can cause further problems for their immunity.

- **Risk of infecting others remains, as before.**

- There is also the new risk that, if the patient has poor adherence to ART and has developed a resistant HIV virus, that transmission of a resistant virus could occur, which is even more dangerous. Therefore we need to continue to emphasize safer sex.

Integrated prevention into HIV care and ART means that on every clinic visit, you need to reinforce prevention, by educating, checking up on key prevention interventions that apply for each patient, providing condoms, demonstrating condom use when needed, etc.

**EXERCISE 13-1**

Break into small groups and discuss:

How can introducing ART help me to improve prevention efforts in our health facility?

In my health facility, have there been barriers to discussing HIV/AIDS and preventive interventions? Can access to ART help overcome them?

Are there myths about ART that will interfere with prevention efforts? List them and discuss ways to counter them.
MODES OF TRANSMISSION OF HIV

Getting infected with HIV does not happen as easily as for instance, getting measles or influenza. Viruses like measles and influenza are transmitted by air, when having social contacts with infected people.

HIV needs 'transport' to get into the body of a person. This 'transport' can be blood, semen, vaginal fluid or breast milk.

As a consequence, the HIV can be transmitted through:

- Sexual relations with an infected person
- Transfusion with contaminated blood or blood products
- The use of needles, syringes and cutting or perforating objects with contaminated blood
- Blood of an infected mother infecting the baby during pregnancy or delivery
- Breast milk of an infected mother during breastfeeding.

TRANSMISSION THROUGH SEXUAL RELATIONS

Sex with an infected person is responsible for the majority of HIV infections. HIV is a sexually transmitted infection.

However, different types of sexual relations have different degrees of risk to get infected.

**Anal sex**

Amongst sexual practices, anal sex represents the biggest risk of contamination if one of the partners is HIV infected.

The anal sex practice represents the biggest risk because the anal mucosa does not produce a natural lubrication, is fragile, and wounds and bleeds very easily.

The penis can have micro-lesions, which permit the entrance of the virus.

**Vaginal sex**

The HIV can be found in large quantities in the semen, and to a lesser amount in vaginal secretions of infected persons. The risk of contamination is still high, but less than with anal sex, because the vagina produces a natural lubrication, and is more elastic.

Vaginal sex represents a serious risk because the vaginal mucosa can still have micro-lesions during penetration, which permits the entry of the virus.

The HIV from the vaginal secretion can penetrate the penis through micro-lesions.
**Oral sex**

The term 'oral sex' means there is contact between the genitals and the mouth. Compared to anal and vaginal sex, oral sex represents the smallest risk for infection. However, very small wounds in the mouth can increase the risk of infection.

**Important:**

The presence of sexually transmitted infections (discharge, ulcers) increases the risk of acquiring and transmitting HIV. This is because people with a sexually transmitted infection have a higher concentration of HIV in the genital mucosa, and/or because the entry of the virus is facilitated due to the presence of lesions in the mucosa.

**TRANSMISSION THROUGH BLOOD**

The blood is an important way of transmitting HIV. HIV can be transmitted through:
- Transfusion of contaminated blood
- Contaminated blood derivatives
- Needles and syringes with contaminated blood (even small quantities)
- Perforating or cutting instruments with rests of contaminated blood

**TRANSMISSION FROM MOTHER TO CHILD**

Around one third of children born from an infected mother will get HIV. Many things can be done to lower transmission from mother to child—see Chapter 14.

**By blood**

When the mother is infected, transmission of the virus to the baby can occur during pregnancy (through the placenta), but the major risk is during labor and delivery.

**By breastfeeding**

The breast milk of an infected mother contains HIV, which can infect the baby.

**HOW HIV IS NOT TRANSMITTED**

HIV is NOT transmitted by:
- Other body fluids like tears, saliva, sweat and urine.
- Personal contacts: kisses on the mouth, hugging, shaking each other's hand.
- Social contacts: during the work, in school, cinema, theatre, restaurant, and sauna.
- Air or water: sneezing, coughing, swimming pool, swimming in the sea.
- Objectives: domestic material, pens, toilets, towels, sheets, soap.
- Insects: mosquito bites or other insects.
WAYS TO PREVENT INFECTION WITH HIV

Even though effective treatments to control HIV exist now, there is still no treatment that cures HIV. A treatment is for life, and might have annoying side effects. Some viruses have become resistant. There is still no vaccine for HIV.

→ All this makes prevention of getting HIV so important.

*Prevention in sexual relationships:*

In general, the key principles are:

- no contact with semen or vaginal secretions
- avoid contact between mouth and penis or vagina

The use of the condom is essential.

Important considerations when using the male condom:

- Look at the expiry date
- Check that the package is not damaged
- Prefer already lubricated condoms
- In case for need for lubricants, use only water-based ones, not petroleum based or oil based, because they give alterations in the latex.

Encourage disclosure and testing of partner(s).

*Prevention of mother to child transmission*

Antiretroviral drugs, together with measures during delivery and modified infant feeding options, can reduce the risk of HIV transmission from mother to child. This subject is covered in chapter 14 and PMTCT materials.

*Prevention of transmission through blood and instruments*

Testing of blood, sterilization of material, and no sharing of instruments and needles are some of the measures to be taken to prevent infection. These topics are covered in other manuals.
EXERCISE 13-2

The trainer will divide you into small groups. Discuss within your group about different beliefs in your community concerning modes of transmission and prevention, even if you do not believe in them yourself. One person of each group will report the findings to the class. The class will then give their comments, and how they would convince patients with such beliefs that these beliefs are not always correct.

You can use the space below to make some notes of the discussions:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

EXERCISE 13-3

The trainer will now ask every one of you to say out loud a mode of transmission, until everybody has said a mode of transmission. If the group is big, some modes of transmission will be repeated several times. This will help you to memorize this topic.

EXERCISE 13-4

You will receive several male condoms and models of a male penis. Explain and demonstrate to your neighbour how to use the condom. Use your neighbour's comments to improve your explanation. When you feel confident, your neighbour will now explain to you. If you feel uncomfortable doing this exercise, do not hesitate to call the trainer.

EXERCISE 13-5

The trainer will draw 2 different rivers on the ground. One river is the 'TRUE' river, the other is the 'FALSE' river. The trainer will now read a phrase about transmission of HIV. When you agree with this phrase, jump quickly in the 'TRUE' river. If you don't agree, jump in the 'FALSE' river. The trainer will give the sign when to jump.

EXERCISE 13-6

Your facilitator will help you list out the key prevention interventions and which patients each is relevant to
Chapter 14: Special considerations for ART in pregnant and post-partum women

Learning objectives

By the end of this chapter you should be able to:

- determine eligibility for ART in pregnant women;
- know which ARV drugs pregnant women can take;
- explain the difference between ART and ARV prophylaxis to prevent MTCT;
- describe special considerations for ART adherence during pregnancy and post-partum;
- make sure women get PMTCT interventions.

Maria is now pregnant. She is very happy, but wants to know whether the ART can harm the baby, and whether she should continue or not. What do you think?

First read section 8.6 of Chronic HIV Care with ART module, then this chapter.
When to give ART to pregnant women

Most HIV+ pregnant women are too early in their infection to be medically eligible for ARV therapy for their own health. The medical eligibility criteria for pregnant women are the same as for other adults.

The main concerns relate to giving ART during the first-trimester when the theoretical risk to the fetus is highest.

For women who are medically eligible for ART and severely ill, the benefits of ART outweigh any theoretical risk to the fetus. For patients in stage 3, it is important to obtain a CD4 count if this is possible, to be sure that they require ART.

It is best to use drugs where there is experience in pregnancy and data to support their prevention of transmission to the fetus. These drugs include ZDV (AZT), 3TC, and NVP.

For women who are medically eligible with less advanced disease, delay until the second trimester can be considered. There are (small) risks and benefits to either choice. Discuss with the woman and consult with the district clinician.

Women who are not eligible for ART should be offered a standard ARV prophylaxis regimen to prevent HIV transmission to their infant, according to national policy. The simplest regimen consists of single-dose NVP at onset of labour plus single dose NVP for the infant soon after birth. Other even more effective regimens start treating the mother at 28 weeks of pregnancy.

Infants born to women receiving ART should receive one-week ZDV or single-dose NVP or both one-week ZDV and single-dose NVP. Follow your national PMTCT ARV prophylaxis policy (write in):

__________________________________________________________________________________________

__________________________________________________________________________________________
What is MTCT?
What is PMTCT?

Mother-to-child transmission (MTCT) of HIV is also known as vertical transmission. This refers to infants who acquire HIV infection from their mothers. Transmission of HIV from mother to child can take place during pregnancy, during labour and delivery, or after birth through breast-feeding. Without intervention, about one-third of children born to an HIV positive mother will acquire HIV.

PMTCT is the prevention (P) of MTCT.

Women who are on ART do not need additional ARV prophylaxis; however, some prophylactic treatment should usually be given to the newborn—follow the guidelines in your PMTCT programme. Continue ART during labour.

No matter what the ARV prophylaxis guidelines, all women on ART still need the other PMTCT interventions:

- counselling on reproductive choice and family planning to prevent unintended pregnancy
- safer labour and delivery
- safer infant feeding

Counselling on reproductive choice and infant feeding choice requires special training. If you have not been trained to provide these PMTCT interventions, refer the patient to someone who has been trained. And try to get this training yourself!
Special precautions in pregnant women

Some antiretroviral drugs may be harmful for the unborn baby if the mother takes them. That is why we need to determine the pregnancy status before deciding which drugs to give.

ZDV-3TC-NVP is a good combination for pregnant women.
   The fixed drug combination d4T-3TC-NVP is a good alternative.

It is essential to avoid starting efavirenz (EFV) during the first trimester of pregnancy (note that this is a change from previous guidelines which say all of pregnancy). This is because it may be harmful for the small foetus. Also avoid the combination of DDI with d4T, which can be very toxic to the mother!

See section 8.6 and call for advice. It is important to be able to start ART in pregnant women at the first-level facility because that is where they are given antenatal care and referral is often difficult and limits access.

Make sure that HIV+ women are offered the appropriate option:
   o ART when the mother is medically eligible plus prophylaxis to the newborn
   or
   o ARV prophylaxis to both mother and baby when the mother is not yet medically eligible for ART.

These are both very important interventions to prevent mother to child transmission of HIV (PMTCT).

Adherence in pregnant and post-partum women

Adherence to ART can be more difficult during pregnancy because of morning sickness and GI upset which can be made worse by nausea from ART.

Women may be hesitant about taking ARV drugs during pregnancy because of fears that it will harm the fetus.

Physical changes post-partum, the demands of caring for the newborn baby, and post-partum depression can all make adherence difficult in the post-partum period.

All these point to the need for special attention to adherence and support to the woman.

ART and breastfeeding: If the woman has decided to breastfeed after infant feeding counselling, she should continue her current ART regimen while breastfeeding. The results of studies to see if this will help prevent transmission through breast milk are not yet available.
Make sure mother receives insecticide-treated bednets for malaria and prompt treatment of any other infections: malaria, TB, STIs

See IMPAC or other pregnancy guidelines.

Make sure PMTCT interventions are received

1. Family planning to prevent unwanted pregnancy

2. ARV prophylaxis or ART to the mother and ARV prophylaxis to the baby

3. Safer labour and delivery

4. Safer infant feeding (counsel on choice)
The mother should make the final choice about the method of infant feeding, after adequate infant feeding counselling. If you have not been trained to provide this, refer her to a colleague who has. Whatever feeding choice the mother makes, it is important to provide support to both ensure optimal nutrition for the infant and to minimize the risk of HIV transmission. For example, if breastfeeding is chosen, it is important that it be breastfeeding only (exclusive breastfeeding) during the first few months then a transition to replacement feeding.
EXERCISE 14-1

Circle the first-line regimens which are safe to give during pregnancy in a woman who does not have anaemia.

- d4T-3TC-NVP
- d4T-3TC-EFV
- ZDV-3TC-NVP
- ZDV-3TC-EFV

EXERCISE 14-2

1. A 22-year-old woman comes to the consultation. She has been sent for testing by the antenatal care nurse. She is HIV+, but is very surprised, since she feels very healthy and does not suffer from any disease. The physical exam is normal. She is 4 months pregnant. You assess her and conclude that she is clinical stage 1. What type of intervention(s) does this woman need?

2. A 25-year-old HIV+ woman is pregnant. You think she must be no further then 2 months. She is thin and she had just started TB treatment for smear negative pulmonary TB. She also had oral thrush 2 weeks ago. What will you do?

3. A 26-year old HIV+ woman is 3 months pregnant. She feels fine and has no problems. On one side of the trunk, you see scars from herpes zoster. What will you do?

4. A 24-year-old woman has been taking ART for 2 years. She tolerates the therapy, and is adherent. Her weight has increased and she has not had any serious OIs lately. She was in stage 4 when she started ART. Her regimen is . She is now pregnant in her first trimester. What will you do?

What would you do if she were pregnant in her second trimester?

5. A woman is taking AZT-3TC-EFV. Before, she took d4T-3TC-NVP, but she had to interrupt it because she had a severe rash on NVP. Now she comes to the health centre and tells you she is pregnant in her 1st trimester. When she started ART, she was in stage 4, but now she feels fine. What will you do?
Introduction

HIV infection in children occurs in the context of an immature immune system resulting in more frequent and severe common infections and an increase in opportunistic infections. Although HIV-infected infants are generally asymptomatic at birth, most of them develop severe symptoms in the first two years of life and die. This chapter describes the peculiarities of HIV infection in children.

Learning objectives:

By the end of this chapter you should be able to:

- describe the key differences in chronic HIV care between adults and children;
- learn how to diagnose HIV infection in children and do clinical staging;
- describe initiation and monitoring of ART in children;
- understand important opportunistic infections in children;
- describe the nutritional and psychosocial needs to support children with HIV/AIDS;
- be able to effectively communicate to children and their caregivers.

Use section 12 of the Chronic HIV Care Module

Key differences in chronic HIV care between adults and children

1. Young children have immature immune systems and thus are susceptible to common infections as well as opportunistic infections.

2. Due to maternally-acquired antibodies, a positive rapid HIV test is not definitive for children below 18 months. However, a negative test is useful because it excludes infection acquired from the mother.

3. Normal CD4 counts are higher in young children than in adults and decrease with age to reach adult levels around the age of 6 years.

4. ARV drugs are handled differently in children's bodies, affecting the doses that are needed. Dosages in children need to be adjusted to weight as the child continues to grow.

5. Counselling children for disclosure of their HIV status, to discuss ART, and to support adherence to ART requires special skills in communication.
Diagnosis of HIV infection in children

Because of the passive transfer of maternal antibodies, HIV antibody tests cannot be reliably used for diagnosis of HIV infection in children aged less than 18 months. Thus a definitive diagnosis of infection will need to wait until the child reaches the age of 18 months. HIV infection in these children can only be confirmed by tests (for example, viral culture and PCR) that detect the virus. These tests are expensive and are usually not available at your level. However, a negative HIV antibody test will rule out maternally acquired infection.

Thus there will be three groups of children born to HIV-infected women:
Group 1: children with negative tests
Group 2: children with positive test but not infected
Group 3: children with a positive test and infected.

The infants and children who are infected need chronic HIV care including antiretroviral therapy (ART) and follow-up (flow diagram below). The acute care of children is addressed by the IMCI guidelines adapted for HIV. The general principles of good chronic care and the general sequence of care in the Chronic HIV Care including ART module apply in these children. However, there are important differences which are described in this chapter.
Use the HIV adapted IMCI guidelines to identify likely symptomatic HIV cases in children below 5 years.

Overview of IMCI

The case management process of IMCI is presented on a series of charts which show the sequence of steps and provide information for performing them. The charts describe the following steps:

- Assess the sick child
- Classify the illness
- Identify treatment
- Treat the child
- Counsel the mother
- Give follow up care

These steps are probably similar to the way you care for the sick child according to the conventional training though you could have learnt different words to describe them. The step called “asses and classify the illness” means taking a history and doing a physical examination. “classify the illness” means making a decision on the severity of the illness. You will select a category of classification for each of the child major symptoms which corresponds to the severity of the disease. Classifications are not specific disease diagnoses. Instead, they are categories that are used to determine treatment.

The charts recommend appropriate treatment for each classification. When using this process, selecting a classification the chart is sufficient to allow you “identify treatment” for a child. For example a child with classification VERY SEVERE FEBRILE Disease could have meningitis, severe malaria or septicaemia. The treatments listed for VERY SEVERE FEBRILE DISEASE will be appropriate because they have been chosen to cover the most important diseases in that classification.

“Treat” means giving treatment in the clinic, prescribing drugs or other treatments to be given at home and also teaching the mother how to carry out the treatments. “Counsel the mother” includes assessing how the child is fed and telling her about the foods and fruits to give the child and when to bring the child back to the clinic.

A two step process is used to identify likely symptomatic cases:

1) An initial screening for four conditions (using IMCI classifications) and

2) A more complete assessment if any one of the four conditions is present. If on assessment, two conditions are present, the child is classified as symptomatic HIV.

Check for suspected HIV in any child found to have any of these HIV-related conditions AND has no danger sign/indication to refer urgently.

- Pneumonia
- Persistent diarrhoea now or by history
- Ear discharge (acute or chronic)
- Very low weight for age.
**ASK:**

- Has the child been tested for HIV?
  - If not, does the mother know her HIV test status?

**LOOK AND FEEL:**

- Very low weight
- Oral thrush
- Enlarged, palpable lymph nodes in more than one site (neck, armpit, groin)
- Parotid enlargement

---

**CLASSIFY FOR SYMPTOMATIC HIV INFECTION**

<table>
<thead>
<tr>
<th>Positive HIV test in child &gt; 18 months of age</th>
<th>HIV INFECTION*</th>
<th>POSSIBLE SYMPTOMATIC HIV INFECTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>❑ Start cotrimoxazole prophylaxis (section 12.5)</td>
<td>❑ Treat any other classification found</td>
</tr>
<tr>
<td></td>
<td>❑ Follow up in 1 month</td>
<td>❑ Counsel on benefit of HIV test for child and mother and do test, or refer for VCT (unless done already).</td>
</tr>
<tr>
<td></td>
<td>❑ Refer for assessment for ART</td>
<td>❑ Advise to attend early for any new problem</td>
</tr>
<tr>
<td>Mother positive (child not tested, or &lt; 18 mo) OR</td>
<td>POSSIBLE SYMPTOMATIC HIV INFECTION</td>
<td>❑ Start cotrimoxazole prophylaxis</td>
</tr>
<tr>
<td>Two or more HIV-related conditions:</td>
<td></td>
<td>❑ Give multivitamin supplements</td>
</tr>
<tr>
<td>• Pneumonia now</td>
<td></td>
<td>❑ Follow up in 14 days</td>
</tr>
<tr>
<td>• Persistent diarrhoea now</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Ear discharge now</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Very low weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Oral thrush</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Enlarged, palpable lymph nodes in more than one site (neck, armpit, groin)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Parotid enlargement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>One HIV related condition</td>
<td>SYMPTOMATIC HIV UNLIKELY</td>
<td>❑ Treat and advise for any other classification</td>
</tr>
<tr>
<td>❑ Counsel on the benefit of an HIV test and how to avoid HIV infection</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* A known HIV case without symptoms should be managed in a similar way.
WHO revised paediatric clinical staging

HIV disease in children may manifest in two ways: AIDS-defining illness such as pneumocystis carinii pneumonia (a kind of severe pneumonia) or non-specific forms such as severe malnutrition, swollen glands, enlarged liver or spleen.

The WHO clinical staging will help you to estimate the degree of immune deficiency the child has. A stage I and II clinical status indicates that the immune system is not yet seriously affected. Stage III and IV indicates advanced immune deficiency. The bottom row indicates when ART is given.
### WHO paediatric clinical staging

(any one condition in the highest staging is adequate)\(^3\)

<table>
<thead>
<tr>
<th>Growth</th>
<th>WHO Paediatric Clinical Stage 1 Asymptomatic</th>
<th>WHO Paediatric Clinical Stage 2 Mild Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms/ signs</td>
<td>No symptoms or only: Persistent generalized lymphadenopathy</td>
<td>Enlarged liver and/or spleen Enlarged parotid Minor mucocutaneous conditions (e.g. Chronic dermatitis, fungal infections or molluscum contagiosum) Chronic/recurrent URTI (sinusitis, ear infections, pharyngitis, bronchitis) Herpes zoster Recurrent mouth ulcerations</td>
</tr>
</tbody>
</table>

#### ARV Therapy

**Indicated only if CD4 is available:**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 18 months &amp; CD4 &lt; 25% (&lt;1500 cells/mm³)</td>
<td>Indicated only if CD4 or TLC is available: Same as stage I OR &lt; 18 months &amp; TLC &lt; 3400 cells/mm³</td>
</tr>
<tr>
<td>18 mo -5 yrs &amp; CD4 &lt; 15% (&lt;500 cells/mm³)</td>
<td>18 mo -5 yrs &amp; TLC &lt; 500 cells/mm³</td>
</tr>
<tr>
<td>&gt; 5 yrs &amp; CD4 &lt;10% (&lt;200 cells/mm³)</td>
<td>&gt; 5 yrs and TLC &lt; 200 cells/mm³</td>
</tr>
</tbody>
</table>

---

\(^3\) Note that these are interim recommendations and may be subject to change.
<table>
<thead>
<tr>
<th><strong>WHO Paediatric Clinical Stage 3</strong></th>
<th><strong>WHO Paediatric Clinical Stage 4</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate unexplained malnutrition not adequately responding to standard therapy (Very low weight for age or Low height for age or Low weight for height)</td>
<td>Severe refractory wasting/ Severe malnutrition unexplained and not adequately responding to standard therapy</td>
</tr>
<tr>
<td><strong>WHO Paediatric Clinical Stage 4</strong></td>
<td><strong>Severe Disease (AIDS)</strong></td>
</tr>
<tr>
<td>Oral thrush (outside neonatal period) or hairy leukoplakia</td>
<td>Oesophageal thrush</td>
</tr>
<tr>
<td>Unexplained and unresponsive to standard therapy:</td>
<td>More than one month of herpes simplex ulcerations</td>
</tr>
<tr>
<td>o Diarrhoea &gt;14 days</td>
<td>Severe multiple or recurrent bacterial infections ≥ 2 episodes in a year (not including pneumonia)</td>
</tr>
<tr>
<td>o Fever &gt;1 month</td>
<td>( Pneumocystis ) pneumonia (PCP)*</td>
</tr>
<tr>
<td>o Thrombocytopenia* (&lt;50,000/mm³ for &gt; mo)</td>
<td>Kaposi's sarcoma</td>
</tr>
<tr>
<td>o Neutropenia* (&lt;1000/mm³ for 1 mo)</td>
<td>Extrapulmonary tuberculosis*</td>
</tr>
<tr>
<td>o Anaemia for &gt;1 month (haemoglobin &lt; 8 gm)*</td>
<td>Toxoplasma brain abscess*</td>
</tr>
<tr>
<td>Recurrent severe bacterial pneumonia</td>
<td>Cryptococcal meningitis*</td>
</tr>
<tr>
<td>Pulmonary TB</td>
<td>HIV encephalopathy*</td>
</tr>
<tr>
<td>Symptomatic LIP*</td>
<td></td>
</tr>
<tr>
<td>Acute necrotizing ulcerative gingivitis/periodontitis</td>
<td></td>
</tr>
</tbody>
</table>

**Start ART:**

All children irrespective of CD4 or TLC; in children > 18 months, treat guided by CD4, if available, especially in LIP, oral hairy leukoplakia or low platelet count.

**Start ART irrespectively of CD4 count**

Start ART in presumptive clinical stage 4 where CD4 is not available:

< 18 months with a combination of 2 or more of the following: oral thrush, severe pneumonia, severe wasting malnutrition or sepsis

---

*Except TB lymphadenopathy*
For staging cases clinically, refer to the definitions given on pages 24-25 for most of the clinical conditions used for clinical staging for adults which are generally similar for children (for example, Kaposi sarcoma or oesophageal thrush). Persistent diarrhoea is persistent or recurrent diarrhoea more than 14 days (this is the same definition as in IMCI and the IMAI Acute Care guideline modules) but differ from the stage III condition in adults where a month or more of diarrhoea is required. Other conditions specific to children are defined below.

**Severe Malnutrition** - is defined as either visible wasting or weight for age <-3 SD

**Generalized persistent lymphadenopathy** - development of persistent, non-inguinal lymphadenopathy in early infancy, consisting of enlarged lymph nodes (>0.5 cm) in two or more regions other than the inguinal area without any apparent underlying cause.

**Parotid enlargement** - chronic parotid enlargement is defined as one-sided or bilateral parotid swelling (just in front of the ear) with or without pain and fever and persisting for more than 2 weeks.

**Encephalopathy** - Failure to attain or loss of developmental milestones or loss of intellectual ability; impaired brain growth or acquired microcephaly

**Lymphoid interstitial pneumonia (LIP)** - Slowly progressive interstitial lung disease with bilateral reticulonodular interstitial pulmonary infiltrates present on chest X-ray for > 2 months with no pathogen identified and no response to antibiotic treatment. Occurs among children more than 2 years old.

**Pneumocystitis carinii pneumonia** - Severe pneumonia with cyanosis in a child less than one year old or dyspnoea on exertion or non-productive cough of recent onset in older children with chest X-ray evidence of diffuse bilateral interstitial infiltrates and no evidence of a bacterial pneumonia.

**EXERCISE 15-1**

Using the revised WHO paediatric clinical staging, in which clinical stage do these HIV positive children with the following presentation but no other signs belong?

1) 4 years old with many lymph nodes more than 0.5 cm in diameter in the axilla, groin and neck without underlying cause

2) 6 months old not feeding well and severe weight loss

3) 9 months old with persistent diarrhoea and vesicular lesions following single dermatome distribution

4) 3 years old with persistent lymphadenopathy and recurrent severe pneumonia

5) 9 years old with Kaposi's sarcoma, otherwise well.

6) 12 months old baby doing very well but whose mother is HIV positive
COTRIMOXAZOLE PROPHYLAXIS

Cotrimoxazole prophylaxis should be offered to children:

- **HIV-exposed child:** All start at 4-6 wks or when first seen.
  - HIV exposure defined as 1st 18 months after born to HIV-infected mother (until infection can be excluded).
  - Breastfeeding child any age.
- **HIV-infected child**
  - Start CTX if:
    - No CD4 testing is available:
      - Clinically symptomatic (WHO stage 2, 3, 4).
      - Note: countries may choose to recommend for children of all clinical stages (WHO 1, 2, 3, 4)
    - CD4 testing is available:
      - CD4 guided: 1-5 years, <25%; >6 yrs, national adult recommendations (<200, 350 or 500).

**Dosage**

Cotrimoxazole syrup is administered once daily. If syrup is unavailable, crushed tablets or paediatric tablets may be used (health workers may switch from syrup to tablets to ensure continuous access to medication).

<table>
<thead>
<tr>
<th>Age</th>
<th>Dosage of cotrimoxazole</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>120 mg tablet or syrup</td>
</tr>
<tr>
<td>6 months to 5 years</td>
<td>240 mg tablet or syrup</td>
</tr>
<tr>
<td>&gt; 5 years</td>
<td>480 mg tablet</td>
</tr>
</tbody>
</table>

**Prophylaxis** continues until ART is initiated and doctor decides to stop it.

Side effects of cotrimoxazole are the same in children and adults. See section 7.2 of the *Chronic HIV Care module*.

**INH prophylaxis** Refer to national guideline.

<table>
<thead>
<tr>
<th>Whom to give prophylaxis (after active TB disease is excluded)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Infants born to HIV-infected women diagnosed with TB disease who started treatment &lt;2 months before delivery</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Infants and children with exposure to an adult with active TB disease</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prophylaxis dosage</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Isoniazid 5-10 mg/kg orally once daily for 6 months.</td>
<td></td>
</tr>
</tbody>
</table>
PREPARATION FOR ADHERENCE

Adherence is the cornerstone of successful ART in children. In the case of the child it is important that the child is involved depending on his/her age and maturity. Follow the same principles as for adults as presented in section 8.9 of the *Chronic HIV Care*.

**Case:** 5 year old James comes to Mulago hospital for follow up regularly for his ART. James is supported by his grandmother. Grandma says James reminds her every evening or every morning that he needs to take his medicines. James knows that taking his medicines everyday is important. Jame's involvement has helped in ensuring adherence.

In the case of a child, adherence can be supported by:
- Involving caregivers and child depending on age and maturity through several counselling sessions.
- Involving school nurses or orphanage staff, where applicable
- Adjusting dosage according to changing body weight during f/up visits
- Selecting appropriate drug formulations considering such factors such as taste and pill load
- Choosing regimens similar to parents where it is appropriate

**Case:** J.O. is 5 years old female. Both parents are dead. She had persistent diarrhea and chronic cough. She looked skin and bone. She was brought by her grandmother. They were given 3 sessions of adherence counselling in preparation for ART. Then she was sent home on ART. Two months later, the cousin brought J.O. back. This time, J.O. was critically sick with overwhelming septicaemia. She had TB of the lungs. The CD4 count was just 7 (way below normal). J.O. did not take the medicines. J.O was admitted to hospital and treated. And she improved remarkably. Discuss how to prepare J.O. for adherence this time round.

STABILIZING THE PATIENT BEFORE INITIATION OF ART

See section 8.1 in the *Chronic HIV Care Module* for the 7 requirements to initiate ART at the health centre level. In principle, all of them apply for children. Medical eligibility is based on paediatric clinical staging and as indicated in the 3rd requirement, the decision to start on ART is made by a doctor at district level because of the need for expertise to decide on the clinical staging and the limited experience in the use of these drugs in children.

There are similar considerations in treating opportunistic infections in children as there are in adults. See the table on the next page (similar to the adult table on section 8.2 of the *Chronic HIV Care module*):
Treat opportunistic infections in children before starting ART

<table>
<thead>
<tr>
<th>If child has this opportunistic infection or other clinical problem:</th>
<th>Follow these instructions (using IMCI guidelines):</th>
</tr>
</thead>
</table>
| **Severe illness or any severe classification in IMCI**  
  (e.g. severe pneumonia) | Refer to hospital for treatment and to decide ARV regimen. Follow treatment plan when child returns. |
| **Non-severe pneumonia** | Treat as in IMCI or national guidelines.  
  (malaria, UTI, sore throat). Do not start ART until treatment completed and no longer febrile. Refer if persistent fever. |
| **Other acute infections**  
  (malaria, UTI, sore throat) | Treat with antibiotics, preferably amoxicillin. Wait for two weeks (to be sure this was not TB) before starting ART. If no improvement, Refer. |
| **Drug reactions** | Do not start ART during an acute reaction. If already on ART, section 8.12) |
| **Prurigo or other known chronic skin problems** | Do not delay ARV therapy. Manage chronic skin problems. |
| **Oesophageal thrush and able to swallow fluconazole** | Start ART after fluconazole treatment if able to swallow. If not able to swallow, refer. |
| **Persistent diarrhoea** | Put on nutritional management and rehydrate (use IMCI guidelines). Do not delay ART waiting for resolution. |
| **Anaemia** | Refer if severe anaemia. Start treatment for non-severe anaemia (use IMCI guidelines). Do not delay ART. |
| **Persistent fever without explanation** | Refer for evaluation by district medical officer. |

Treat tuberculosis before initiating ART

Refer to national guidelines for treatment of tuberculosis in children. The guidelines are similar to those for adults. A doctor/medical officer should make these decisions.
First line ARV regimens for children

A doctor will initiate ART based on the clinical staging and CD4 count if available. The clinical staging table indicates when the child is medically eligible for ART. Use the national guidelines to make decisions.

PROPOSED CLINICAL CRITERIA FOR INITIATING ART
(in infants and children <14 years)

<table>
<thead>
<tr>
<th>Clinical Stage</th>
<th>Therapeutic step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 4</td>
<td>Start ART</td>
</tr>
<tr>
<td>Presumptive Stage 4</td>
<td>Start ART</td>
</tr>
<tr>
<td>Stage 3</td>
<td>Consider treatment for all ages. Young infants and children &lt;2 years require ART more urgently. If available, CD4 should be used to guide treatment decision.</td>
</tr>
<tr>
<td>Stage 1 and 2</td>
<td>&lt;13 months: CD4 &lt;20%</td>
</tr>
<tr>
<td></td>
<td>13 months - 6 years: CD4 &lt;15%</td>
</tr>
<tr>
<td></td>
<td>≥6 years: CD4 &lt;200/mm³</td>
</tr>
</tbody>
</table>

Note: All HIV exposed children (until HIV infection is definitively ruled out) and HIV infected children with any signs or symptoms of HIV should be given cotrimoxizole prophylaxis.

Recommended first line ARV regimens

AZT or d4T + 3TC + NVP or EFV
AZT + 3TC + NVP
AZT + 3TC + EFV
d4T + 3TC + NVP
d4T + 3TC + EFV

ABC +3TC + NVP or EFV
ABC +3TC + NVP
ABC +3TC + EFV

* If <3 years or <10 kg, use NVP. EFV cannot be used in these children.
**ARV drug preparations for children**

Liquid formulations may not be easily available, and even when they are, they may be more expensive. In resource poor settings, there are often difficulties with storage. Refrigeration may be required. It is important to pay attention to the shelf life of liquid antiretroviral preparations.

Some tablets and capsules come in low enough doses to enable accurate dosing for children of most ages (e.g., d4T capsules come in 15, 20, and 30 mg strength, and NFV (nelfinavir) has scored tablets that can be halved). For those tablets that are not available in appropriate doses for children, health providers and caregivers should be aware of the problems of cutting them up:

- Under-dosing of drugs is possible, which can lead to increased risk of resistance;
- Over-dosing of drugs is possible, which can lead to increased risk of toxicity;
- The doses cannot be easily adjusted as the child grows; and
- Some drug combination tablets (e.g., fixed dose ZDV/3TC) do not have the ZDV and 3TC components evenly distributed through the tablet and therefore cutting them could result in wrong dose of either component.
- Some drug combination tablets (e.g., fixed dose ZDV/3TC) do not have the ZDV and 3TC components evenly distributed through the tablet and therefore cutting them could result in wrong dose of either component.

**Determining paediatric drug dosage**

To ensure that correct ARV doses are dispensed to children, doses should be calculated per kilogram body weight.

However, drug doses may be directly obtained from tables based on “weight band” as shown in on page H70 of the Chronic Care module. Drug doses have to be increased as the child grows; otherwise there is a risk of under dosage and development of resistance. **If the health worker can calculate exact dosage based on weight, this is preferred.** Use the following example:

**EXERCISE 15-2**

10 kg child on d4T

Look at the table for dose per kg. For a child weighing less than 30 kg, the dose is: 1 mg/kg/dose twice daily. Total dose is 1 mg X 10 Kg = 10 mg of d4T.

What are the available preparations? Oral solution: 1 mg/ml

1 mg/ml means 1X 10 mg = 10 ml of solution.
EXERCISE 15-3

A. Practice the dosages for all first-line ARV's and a fixed combination of d4T/3TC/NVP for the following weight groups:

1) 12 month old 10 kg child
2) 10 month old 8 kg child
3) 13 month old 12 kg child
4) 2 year old 10 kg child
5) 3 year old 15 kg child
6) 7 year old 20 kg child
7) 10 year old 30 kg child
8) 10 month old 7 kg child
9) 18 month old 11 kg child
10) 12 year old 25 kg child

B. Optional:
Assuming that these ten children gained weight by 5 kg after a 6 month ARV therapy, recalculate the dosages for first line ARVs and a fixed dose combination "d4T/3TC/NVP"

MONITORING RESPONSE TO ARV THERAPY

In children, it is generally advisable to monitor clinical response as the CD4 count and the percentage are less available. Where CD4 is available, it is a useful adjunct and CD4% is more reliable for children under 6 years than CD4 counts.

Clinical monitoring in children should include:

- Monitoring of weight and height gain, assessing using growth charts
- Developmental milestones;
- Types and frequency of opportunistic infections
- Important clinical signs of antiretroviral drug failure include:
  - Lack of growth response to treatment or
  - Falling off the growth curve in children who show an initial growth response to therapy;
- Loss of neuro-developmental milestones (regression),
- Recurrent oral thrush and other opportunistic infections.

All such children manifesting with signs of drug failure should be referred to the district doctor to consider whether this is drug failure or another problem and to make a decision on switch to second line regimens.
Manage side effects and new symptoms

Presentations to drug side effects could be different in children depending on their age. Young children may not complain of headache but they may become irritable to the pain and manifest reduced feeding and reduced activity. Similarly children may not be able to locate pain on the abdomen or neuritis. Nightmares may be difficult to recognize in the young child. Other than these differences, the side effects of ARV are similar to those of adults. Refer to section 8.12 of the *Chronic HIV Care Module*.

Case: A 5 year old girl was put on "Triomune" triple ARV regimen that contains NVP. Two weeks later she developed a "measles-like" illness. She continued to deteriorate. It did not look true measles. The health worker stopped the ARV regimen. The rash cleared in two days. Discuss how you would manage the case.

**Immune reconstitution syndrome (IRIS)**

Similar to adults, when children are put on ARV, they may respond with immune reconstitution syndrome in the first few (up to 6) weeks after AR. IRIS is less common in children than adults.

**Manage chronic problems**

**Nutritional management**

HIV-related illness, such as tuberculosis and diarrhoea, not only have nutritional status as a significant determinant of their incidence and severity, but they also have severe nutritional consequences that commonly precipitate appetite loss, weight loss and wasting. Clinical situations that may impair the nutrition of HIV infected children are: recurrent or chronic infection, fever, intestinal infections, oral or oesophageal thrush and persistent diarrhoea. Management includes:

- Increase energy intakes by 50% to 100% over normal requirements in children experiencing weight loss.
- Identify the local foods that are available and affordable to advise the caregiver on energy requirements. For the type of local foods, refer to the local food adaptation table, for example, that of IMCI.
- HIV-infected 6-59 months old children should receive vitamin A supplements(100,000 IU for infants up to 12 months, 200,000 IU for children above 12 months) every 4-6 months. This level is consistent with the current WHO recommendations for the prevention of vitamin A deficiency in all children.
- For persistent diarrhoea, refer to IMCI guidelines.
- Feeding and increased fluids should continue during illness. The child may develop nausea and vomiting as a result of ARV drugs. Encourage small frequent fluids and give food that the child likes. Let the child eat before medication. In the child with sores in the mouth, give soft and mashed food or give paracetamol half an hour before solid feeds.
Psychosocial support

Beyond disease management, children infected and affected by HIV are faced by a number of problems that impede the social, educational and emotional development necessary to a child’s evolution and well being.

- Health facility-based and home-based stimulation of children improve their mental, social and emotional development. Children need care through talking, playing and providing a stimulating environment.
- In those children with malnutrition, combining psychosocial stimulation and food supplementation has been shown to result in better growth.
- Children's development will flourish when they form secure attachments to a responsive caregiver. Furthermore the children need to be provided with psychological and emotional support within their family or through other caregivers, and to be able to communicate openly about their own or their family member’s condition so as to give relief to deep fears that are difficult to share.

For caregivers to provide this support to children, they must themselves be provided with psychosocial support. This is best done through community-based organizations, peer support groups, and home visits as feasible. It is important for health facility staff to ensure adequate linkage of families with these groups and to pay attention to the psychosocial needs of the whole family on each visit.

Good communication with children

When communicating with a child, it is useful to be at the same level as he or she is, for example, sitting or lying on the floor. A child who has been traumatised by any situation may find it difficult to trust others and particularly adults. In order to win a child’s trust, adults require patience and must be consistent in their dealings with the child. The child's feelings must be acknowledged as his/her right.

Children speak three "languages" - the language of the body, the language of play, and spoken language. Children often tell their story through their play, their behaviour, and their body language. Through observing the different "languages" of children and how children express their meaning, you can learn about what has happened to the child.

Immunization.

All children whether HIV infected or not should receive the routine immunizations except for BCG and yellow fever which is not given for stage III cases.
EXERCISE 15-4

1. John is a 2 year old boy who has been having cough for 7 days. His mum said he has not been eating well these days. On examination you found John actually has pneumonia. And he has very low weight for his age. What are the next steps?

2. Maria, a 7 month old girl, has been doing well until 3 weeks back when she developed diarrhea which still continued. Since then, Morin's weight has been going down. You weighed her and found that she is very low weight for age. Her buttocks are folded and hanging and the limbs are thin with skin and bone only. How will you work out Morin?

   If you tested Morin and she is HIV positive, how will you manage:
   - feeding?
   - immunization?
   - and her severe malnutrition?

   What preventive measures will you take against opportunistic infections?

3. Jane is 18 months old and HIV positive. You found Jane was able to walk and even climb stairs. Now Jane can only crawl. She has regressed. She has been having persistent diarrhoea for almost a month now and she is severely wasted. How will you plan to address Jane's problem?

4. Jackie, 10 years old female, responded very well to ART initiation. She gained weight. However, on the 3rd week, she developed multiple abscesses. What is the likely diagnosis: opportunistic infections? Drug side effects? Immune reconstitution syndrome? What will you do?

5. Patricia is a 7 year old girl who was being followed up for in the hospital because she is HIV positive. She now presents to the hospital with severe headache and high grade fever. She also has stiff neck. What problem will you consider? What will you do?

   Subsequent investigation on Patricia's condition confirmed cryptococcal meningitis and she was treated for it at the hospital. Patricia was initiated with at the hospital and was referred back to you. How will you follow Patricia? What common side effects will you give advice to the caretaker on? When should they seek care?

6. George is a 5 years old male and HIV positive. He is the second of three siblings. The first and third are seronegative. Both parents are deceased. He lives with his 57 year old grandmother who has 5 other orphans to care for. George developed vesicular and painful lesions on the chest and back following a dermatome distribution. How do you manage George?
Chapter 16: Is ART working?

Learning objectives

By the end of this chapter you should be able to:

- recognise treatment success and failure;
- explain frequency of CD4 monitoring and its interpretation;
- explain frequency of clinical monitoring and its interpretation;
- explain the principles of immune reconstitution syndrome and give some common examples of it.

Maria has been taking her treatment correctly all the time. Her weight is increasing, and she is finally getting rid of these white patches in the mouth.

Maria has been taking her drugs correctly. She feels fine. The only thing that bothers her is that her face has changed. It seems as if her cheeks are hollow, although her weight is fine. She finds it really difficult to accept, and discusses with the nurse.

What could be the cause of this, and what would you do?

The nurse calls for advice and switches the regimen to AZT-3TC-NVP, after checking Maria's Hb.
Maria is really happy. When her child was 18 months old, they went to do an HIV test, and it was negative.

She is now even more convinced to keep on taking the drugs and never forget them, as the nurse keeps on telling her.

Kato has been taking his treatment correctly all the time. His weight is increasing, and he is finally getting rid of the itching.
Kato has a friend to help support him in case he gets discouraged. He feels fine.

Kato keeps on coming to all appointment to the health centre, and never forgets the drugs.

Mr. Richard still has some periods where he does not take the drugs very well. He thinks the nurse is exaggerating when she says you should never miss a dose. He knows several friends who are not so adherent and are still OK. Mr. Richard sometimes likes to drink a lot of beer during the weekend.

The first year, Mr. Richard is OK. He gains weight and has no more rashes on the arms and legs.

The second year, he is still OK.
In the end of the third year, he starts to cough for several weeks. He loses weight. Investigations show he has TB. They say it is because he did not take the ART well.

Mr. Richard started to have the rash on arms and legs, and many other symptoms of opportunistic infection. The nurse has told him the ART is not working anymore, because he has not been adherent. She has referred him to the doctor, to get second-line therapy.

Now Mr. Richard is spending a lot of money to buy the very expensive second line therapy. It is a lot of pills to take, and there are more side effects. He is very unhappy with the situation, but realises he has no other choice, and that the nurse was right.

Remember the goal of ART?

- Antiretroviral therapy does not cure HIV infection.
- ART halts viral replication, thus preventing further disease progression and immune system damage.
- The body’s defence (immune system) gets a chance to recover and less opportunistic infections occur.

The goal of the therapy: reducing the number of virus in the blood as much as possible and increase the number of CD4 as much as possible.

The virus can never be eradicated completely, so the person should take the drugs forever, even if symptoms have disappeared.

Since the virus cannot be eradicated, safe sex has to be practiced.
HOW TO KNOW IF THE GOAL HAS BEEN REACHED?

- Measuring the **number of copies of HIV** in the blood is not yet possible in most resource-poor countries. This test is called the viral load.

- We can use tests that measure the **number of CD4** in the blood, to see how well a combination of drugs is working for the patient. The best way to use these tests is to measure the CD4 count **before the patient starts therapy or changes therapy**, then every 6 months.

  The time it takes to have increasing CD4 varies from person to person. The increase in CD4 can be around 100-200 in the first year if the patient did not take ART before, and is taking the drugs well. Much depends on where you start: sometimes, a lower CD4 when you start ART means it will take longer before the CD4 reaches a good value again.

  When the number of CD4 starts to **decrease** in a patient who is taking ART, it can mean that we do not reach our goal anymore.

  A small decrease in CD4 does not always mean that we do not reach our goal anymore, that's why in case of decrease in CD4 count, we need to call for advice.

  **Clinical monitoring** is an option if there is no CD4 count available to see if we reach the goal of therapy. The goal of our therapy is to increase the number of CD4 cells. When the number of CD4 increases, the body's defence will work better. If the body's defence works better, less opportunistic infections should occur. That is why looking at the clinical status of the patient (evaluating the occurrence of opportunistic infections) is a good way to evaluate if we reach the goal of our therapy. If we reach the goal of our therapy (success), the patient's weight should increase, and no new opportunistic infections should occur. We say a patient has failure of therapy in case new opportunistic infections start to occur, or prior opportunistic infections relapse or symptoms do not disappear over time.

  A very important remark is that clinical failure should not be confused with immune reconstitution syndrome (also known as immune reconstitution inflammatory syndrome (IRIS)) or side effects of the antiretroviral drugs.

  Usually, clinical failure will only appear several months after the drop in CD4. In other words, clinical manifestations of failure of therapy appear later than a drop in CD4.

  In most cases (but not always), new symptoms appearing shortly after starting ART, are due to immune reconstitution syndrome or drug side effects. New symptoms appearing a long time after starting ART are more likely to be failure.

  **If CD4 numbers** decrease in patients taking ART: call for advice.

  **If new symptoms** appear or symptoms do not improve, or the weight is decreasing in patients taking ART: call for advice, because this can be toxicity of drugs, can be immune reconstitution syndrome or can be failure of therapy.

  **New symptoms appearing in the first month of ART** are rarely due to failure.
EXERCISE 16-1

Think of how the life of Flavia and Julio would have been if they had had access to ART. Discuss within the group.

_________________________________________________________________
_________________________________________________________________
___________________________________________________________

EXERCISE 16-2

1. A patient takes for 1 year and 6 months. CD4 was measured at baseline (50), month 6 (143), month 12 (247) and month 18 (233). What will you do and why?

_________________________________________________________________
_________________________________________________________________
___________________________________________________________

2. A patient has been taking ART for 3 years now. At first, the weight was increasing, and he did not have a serious OI since he started treatment. Now, the patient develops itching of the skin, he also had herpes zoster last month. He starts to lose a lot of weight. What will you do and why?

_________________________________________________________________
_________________________________________________________________
___________________________________________________________

3. A patient has been taking ART for 6 months. The CD4 has increased from 2 cells/mm³ at baseline to 60 cells/mm³ now. What would you do and why?

_________________________________________________________________
_________________________________________________________________
___________________________________________________________

4. A patient has been taking ART for 2 weeks. He never took ART before. Now he develops fever and cough. Do you think this is failure of therapy? What would you do?

_________________________________________________________________
_________________________________________________________________
___________________________________________________________
Chapter 17: Arrange - dispense, record data, schedule follow-up

For the provider who dispenses medications, records data and schedules follow-up

(This can serve as a chapter in the clinical course for nurses and clinical officers or for a lay provider with good basic education)

Learning objectives

By the end of this chapter you should be able to:

- describe 3 ways ARV drugs interact with other drugs;
- explain safe storage of ART drugs;
- avoid drug interactions;
- dispense ARV drugs according to treatment plan;
- record drugs dispensed on treatment card and stock card;
- schedule follow-up;
- know how to follow-up on defaulting patients.

This module describes Step 10: Arrange, in the IMAI Chronic HIV Care with ARV Therapy module.
Introduction

Persons who are living with HIV need special care at home and at the clinic. They need education and counselling about how to live with HIV.

Antiretroviral therapy (ART) against the HIV infection is now available. The chronic HIV care clinic provides both ART and treatment for opportunistic infections and other problems. These medications can help many people to live longer, more productive lives.

Patients will come to you for their supply of medications regularly, over what may be a lengthy course of their care. Your task will be to dispense the medications. You will help patients with problems they might have taking the medications. As with all drugs from your clinic, you will need to keep records on the drugs you have given them.

You will also schedule their next follow-up visit to the clinic. If patients miss their scheduled appointments, you will arrange to find out the reasons and, if necessary, arrange home visits.

Persons living with HIV are concerned about their illness and how others will respond to them. You and others on the staff of the clinic can help persons living with HIV to feel welcome and want to return to the clinic for care. You can help them follow their treatment plan, and be confident that this care will make a difference.

1.1 Dispense medications according to treatment plan

Patients will come to you, the dispenser, for medications and counselling on how to take their prescribed medications safely. The dispenser also gives them support in adhering to their treatment plans. Just before seeing the dispenser, a patient may have, for example:

- seen the counsellor for follow-up education and support or
- seen the health worker for a clinical review or
- seen only the registrar, as the patient only needed a supply of medications.

As the last person to see the patient during this clinic session, you will need to make sure that the patient has received appropriate treatment, knows how to take the medications safely, and will be able to adhere to the treatment plan, including the follow-up visit.

Check the treatment plan

Look at the treatment plan on the HIV Care/ART Card, in the top right-hand box.

Review each of the treatments prescribed for the patient and indicated on the card. See the sample card on page.

- Cotrimoxazole
- Other medications

5 The clinic systems, registers, and recording materials will be adapted, as necessary, to fit local conditions. At this time HIV may be removed from the name of the chronic care clinic and the clinic materials.
The patient may receive other treatments, for example, for malaria or other fever, mouth sores, a skin problem, tuberculosis or diarrhoea. These will be listed under Other meds.

- **Antiretroviral (ARV) drugs**
  There may be several antiretroviral (ARV) drugs available in your health facility in a first-line ARV regimen. They are given in combinations appropriate for the patient.
  - nevirapine (NVP)
  - stavudine (d4T)
  - lamivudine (3TC)
  - efavirenz (EFV)
  - zidovudine (ZDV)

The ARV Therapy chart summarizes the combination of treatment and the dosages.

These drugs may have been prescribed previously and the patient is returning for a new supply, or they may have been prescribed for the first time today.

The health worker also has written a date for the next **follow-up visit** on the card and whether the patient should be referred.

**Make sure adherence has been assessed and supported**

Patients are on antiretroviral (ARV) therapy a long time. Health workers prepare patients for ARV therapy during the clinical review and advise patients on the importance of adhering to the treatment. ARV drugs are very strong medicines, but it is essential to maintain high drug levels in the blood for ARV therapy to work. This is true for many medicines, but even more important for the ARV drugs.

Patients must understand that the ARV drugs must be taken:

  - twice daily, without interruption.
  - at the right time, every 12 hours or close to it.
  - not stopped. If the patient stops, he will become ill – not immediately, but after weeks, months or years.
  - not shared with family or friends – patient must take full dose.

If patients do not adhere to the regimen, the drugs can develop resistance and lose their effectiveness in fighting the HIV infection. Patients may have some minor side effects in taking the drugs. For example, the patient may have a rash, nausea and lack of appetite, diarrhoea or dizziness. They need support to deal with these problems so that they do not interrupt their treatment.

If patients agree to start the ARV therapy and adhere to the treatment regimen, health workers then assist them in developing the resources, support and arrangement needed for adherence. These include:

  - Ability to come for required schedule of follow-up.
  - A reasonable food supply.
  - Home and work situation that permits taking medications every 12 hours without stigma.
  - Regular supply of free or affordable medication.
  - Supportive family or friends.
  - ARV adherence support group.
  - Treatment supporter.
Look at the treatment plan on the HIV Care/ART Card for the health worker’s estimate of the patient’s adherence to treatment with cotrimoxazole and ARV drugs.

Make sure that adherence has been assessed, for patients returning for a supply of medications. If adherence was not assessed, ask questions to estimate adherence (see chapter 8 and section 8.9 in the module) and record an estimate of adherence (Good, Fair or Poor or % if pill counts have been done- follow the national guidelines).

1. **To assess the frequency of missing doses of cotrimoxazole and ARV drugs, good questions to ask include:** Many patients taking these medications find it difficult from time to time. They may miss a dose now and then.
   - When was the last time you missed taking your pills? Which pill, or all?
   - How many times have you missed in the past day? The past two days? The past week? Which pill, or all?
   - In an average week, how often do you miss taking your pills?

2. **To assess barriers, ask:** When (time of day) is it most difficult to remember to take your pills? What makes it difficult to take your pills? For which pill, or all?

3. **To assess supports, ask:** What makes it easier for you to take your pills? Is there anyone who helps you?

Fair or poor adherence requires adherence counselling by a lay provider or health worker—make sure that this has happened (see section 8.9 in **Chronic Care Module**).

*Make sure the patient understands how to take the drugs - the dose and the schedule (see Chapter 10)*

1.2 **Identify first-line ARV drug interactions**

Care must be taken for drug interactions when patients are on ARV therapy. As you dispense medications, watch for possible combinations of drugs that may cause drug interactions. These might not have been picked up by the health worker during the clinical review. Also, notice whether the patient’s condition has changed that might be related to a drug reaction.

*Three ways ARV drugs interact with other drugs:*

1. The effects of the drugs on the kidneys and liver

   Besides ART drugs, patients might need to take other drugs. The drugs have an effect on how hard the kidneys and liver work to clear the body of the drugs.

   **Some drugs can make your kidneys and liver work harder, and others can make you kidneys or liver become 'lazy'.**

   - If you take a drug that makes your liver work *harder*, the amount of antiretroviral drugs in the blood will decrease faster. As a result, the amount of antiretroviral drugs will be insufficient, which might create resistance to the treatment.

   - If your liver starts to work *slowly* due to the use of another drug, the amount of antiretroviral drug in the blood might be too high. In this case, the patient might develop toxic blood levels leading to side effects.
2. The toxic effects and side effects of the drugs

Almost all drugs have some toxic effect or side effect. Think about a simple aspirin, which can cause a stomach ulcer. Most people can take aspirin without having a stomach ulcer, only some will have this side effect.

The same is true for antiretroviral drugs. Some antiretroviral drugs are a bit harmful for the liver, other drugs are harmful for the nerves, and others can decrease the production of red blood cells. In most cases, the body will tolerate the drug, without side effects.

In some cases, side effects can occur. **The risk for side effects increases if two or more drugs that have similar side effects are given together.**

3. The way the drugs stop the virus

A drug can reinforce the action of another drug, or block its action, making it ineffective. Different categories of antiretroviral drugs have different ways of stopping the virus from replicating.

Drugs in the WHO/national first-line regimens are known to work well together. Used in the correct combination, the right drugs will **reinforce each other's effect.** That is why it is important to stick with the first-line regimen combinations as recommended in national policy.

Some ARV drugs work in **exactly the same way** to stop the virus. Since they work in exactly the same way, on the same spot in the CD4 cell, there is not enough space to work well, and the drugs will not reinforce each other, but **block each other.** This is the case for zidovudine (ZDV) and stavudine (d4T). These two drugs cannot be given together. In combination, they are ineffective. This is why these drugs are not combined in the WHO first-line regimens and should **not** be given together.

**Important examples of drug interactions:**

- **Avoid giving nevirapine and rifampicin** together

  Rifampicin will make the liver work harder, so the level of nevirapine in the blood will be lower. This can create HIV resistance. Also, both drugs are a bit toxic for the liver. If they are given together, the liver might be damaged (the risk of developing hepatitis increases).

- **Avoid giving nevirapine and ketoconazole** (a drug active against fungal infections) together

  Both drugs are a bit toxic for the liver. When only one drug is given, the liver can handle it. When both drugs are given together, the liver might be damaged. Also due to interactions, the level of nevirapine is increased, and the level of ketoconazole is decreased. This can cause the ketoconazole not to work.

- **Use alternative oral contraception with nevirapine**

  Using ART with oral contraception can make the oral contraception less effective. Counsel your patient to use alternative contraception or an additional method. It is always important to include a condom for dual protection.

- **Avoid giving efavirenz and diazepam** together, except in an emergency requiring diazepam
Efavirenz will make the level of diazepam in the blood higher. This means that your patient will be too sleepy, and for a longer time, because it creates a stronger diazepam effect. This is a problem if diazepam is taken regularly.

This concern should NOT stop you from using rectal or IV diazepam to stop a convulsion.

- Avoid giving stavudine (d4T) and zidovudine (ZDV) together

Stavudine and zidovudine cannot be given together. Both drugs are working on exactly the same spot to prevent the virus to enter the centre of the CD4 cell. Their work is so similar that, instead of helping each other, they prevent each other from doing the work correctly.

- Avoid giving d4T and ddl together.

**Important:**
Drugs interact with each other, which can lose their beneficial effects or be harmful. This is why you must explain to your patients that they cannot take drugs without asking the advice of the health workers in clinic.

**Effects of food on efavirenz**

Food can also have an influence on how well the drugs can be absorbed. For efavirenz (EFV), the presence of fatty food may also have an influence on how well the drug can dissolve. Advise the patient to avoid eating fatty meals.

For the other four ARV drugs in the first-line regimens, there are no food restrictions.

**Review all drugs prescribed on the treatment plan**

Are there any combinations of drugs on the treatment plan that could cause a drug reaction? See the table on section 10.2 in the *Chronic HIV Care module* for a summary of drug interactions and other cautions.

**Check with the patient to see if the patient is taking any other medications or is pregnant**

1. **Ask:** What other drugs are you now taking? Are you taking any traditional or herbal medicines?

2. **If the patient is a woman of childbearing age (12-45 years old), check the HIV Care/ART Card to see if she is pregnant. If not indicated, ask:** Do you think you might be pregnant? Write the response in the place provided on the card.

If you see drugs that can cause a drug reaction or should not be taken if the woman is pregnant, call the clinician to ask for an alternative drug prescription.
Arrange follow-up visits

Use the table on section 10.3 of the *Chronic HIV Care module* to determine interval if the follow-up date has not been written on the patient's card. Mark the follow-up date on the patient's hand-held card.

Keeping track of the patients on ART

If the patient fails to keep a follow-up appointment within a few days, it is important to follow-up. Look at the patient HIV Care/ART Card for the address and the name of the treatment supporter and home-based care contacts. There may be phone numbers. Use these and your community resources to try to contact the patient. Arrange a home visit if necessary.

A general principle of good chronic care:

9. Organize proactive follow-up.

In proactive care, we should be anticipating patient's needs, arranging follow-up, and supporting self-management.

Proactive care can be compared to "reactive care." In this type of care, we just respond to what is most urgent on that day. There is little planning ahead or even looking back to see what happened to patients that we saw last week and asked to come back.

Hanging files.

A hanging file system is one way of identifying those who need tracing. Put a coloured paper clip or other coloured "ticklers" on cards to indicate when the patient is due to return for follow-up.
Exercise 17-1

Written exercise - identifying possible drug reactions

1. For each of the lists (a-h) below, circle the drugs which when given together could have a drug interaction or other difficulty (there may be more than one interaction). Draw a line to link them together. For example:

   nevirapine
   ketoconazole

<table>
<thead>
<tr>
<th>nevirapine</th>
<th>cotrimoxazole</th>
</tr>
</thead>
<tbody>
<tr>
<td>stavudine</td>
<td>rifampicin</td>
</tr>
<tr>
<td>lamivudine</td>
<td>phenobarbitol</td>
</tr>
<tr>
<td>oral contraceptive</td>
<td></td>
</tr>
<tr>
<td>diazepam</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ZDV-3TC-NVP</th>
<th>efavirenz</th>
</tr>
</thead>
<tbody>
<tr>
<td>diazepam</td>
<td>stavudine</td>
</tr>
<tr>
<td>aciclovir</td>
<td>lamivudine</td>
</tr>
<tr>
<td>ganciclovir</td>
<td>diazepam</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>nevirapine</th>
<th>d4T-3TC-EFV</th>
</tr>
</thead>
<tbody>
<tr>
<td>lamivudine</td>
<td>rifampicin</td>
</tr>
<tr>
<td>zidovudine</td>
<td>oral contraceptive</td>
</tr>
<tr>
<td>stavudine</td>
<td>diazepam</td>
</tr>
<tr>
<td>diazepam</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ZDV-3TC-EFV</th>
<th>AZT</th>
</tr>
</thead>
<tbody>
<tr>
<td>rifampicin</td>
<td></td>
</tr>
<tr>
<td>ketoconazole</td>
<td></td>
</tr>
<tr>
<td>phenytoin</td>
<td></td>
</tr>
<tr>
<td>cotrimoxazole</td>
<td></td>
</tr>
</tbody>
</table>
2. If the patient is a woman who is taking an oral contraceptive, what advice would you give?

3. If a patient is being treated for tuberculosis with rifampicin, which ARV drug should he avoid? ________________________________

   For what reason?
   _________________________________________________________________

   What ARV drugs can he take?
   _________________________________________________________________

4. If a patient is taking d4T-3TC-EFV, what other advice would you give the patient?
   _________________________________________________________________
   _________________________________________________________________

   When you have finished, discuss your answers with your facilitator.
Chapter 18: How to work as a clinical team, communication, and how to consult effectively

**Learning objectives**

In this chapter, we will:

- review the General Principles of Good Chronic Care;
- work as a clinical team;
- learn how to consult effectively:
  - learn how to summarize a case then consult by mobile phone to district medical officer or doctor;
  - for MO/MD: learn how to give advice and supervise by phone.
WORKING AS A CLINICAL TEAM

It is important to work well as a clinical team. It improves patient care and makes the work more manageable when the team works together. Even when the medical officer/medical doctor is not physically in the same health centre, the clinical team can be extremely important in good patient care by simple tools such as weekly or biweekly meetings as a team and effective phone consultations.

EFFECTIVE PHONE CONSULTATION FOR HEALTH WORKERS

When to Call/Preparation for Call

- **Keep** phone consultation log and schedule in a secure place so it is readily available when you need it.
- Remain familiar with the IMAI HIV Chronic HIV Care with ART, Acute Care, and Palliative Care guidelines and keep them with you when you consult by phone, so you can refer to them if necessary. Understand when health workers are advised to consult with or refer to a doctor or medical officer.
- If you are not sure when to call, consult your colleagues or health centre supervisor.
- Prior to making the call, **review** patient history and recording form.
- **Assess** which is the most important part of the patient history to present in your initial presentation of the case.
- **Prioritize** your questions and concerns about the patient based on information on the recording form, including lab results.
- Unless it is an emergency, **call** during the designated times following local phone consultation protocol.
- Before you make a call, **move** to a confidential, quiet space, if necessary.
- Have your phone log ready.
How to present the case/Tips for the call:

- Make sure you can both hear each other clearly before you start your case presentation.
- If the doctor is unknown to you, politely determine his or her experience with your clinic and your community if there is an important fact that he or she needs to understand before beginning the consultation.
- Be respectful, brief, concise, and speak very clearly.
- Give your full attention to the call and do not be distracted by activities around you or allow yourself to be interrupted.
- An effective phone consultation solves the problem without making anyone angry or feeling stupid.
- If the doctor asks you a question, understand what the question is by repeating it if appropriate.
- During the call, continue to prioritize your questions and concerns using sound clinical judgment by not eliminating important patient history, symptoms, treatment, etc.
- Be specific and to the point because key facts can be lost in a mass of less important facts.
- If the doctor is giving you more information than you can record or is speaking too fast, politely ask him or her to speak more slowly and to repeat the information.
- Ask the doctor to be specific in his or her recommendations or treatment options. Studies indicate that compliance is improved if recommendations are specific especially for drug recommendations (dose, frequency, route, etc.).
- Respect your own limitations. If you do not understand a question or a medical term, it is appropriate to ask the doctor questions.
- Repeat treatment or recommendations. Continue to ask questions and clarify as necessary.
- Before you hang up, make sure you understand exactly what was said.
- If you need a follow-up call, schedule as appropriate or state when you will call them back.
- Thank them for their help.
- Record call in the phone log.
- Implement the patient plan then record on the patient's card.
EFFECTIVE PHONE CONSULTATIONS FOR DOCTORS OR MEDICAL OFFICERS
BACKING-UP CLINICAL TEAM AT HEALTH CENTRES PROVIDING ART AND
OTHER CHRONIC HIV CARE

Preparing to receive calls:

• Develop and distribute your phone consultation schedule, including emergency
  phone consultation protocols, to clinical staff or your clinical HIV care team(s) who
  will be calling you for consultation.
• Be familiar with the IMAI HIV Chronic HIV Care with ART, Acute Care, and
  Palliative Care guidelines and any other guidelines the health workers are using so
  that you understand what health workers know and for what conditions they are
  advised to consult with you. Keep copies of these guidelines available.

Tips for Calls:

• When you receive a call, move to a confidential, quiet space, if necessary.
• Make sure you can both hear each other clearly before caller starts presentation of
  patient.
• Be respectful, supportive and positive.
• Give your full attention to the caller.
• An effective phone consultation solves the problem without making the health
  worker feel stupid.
• It is not necessary to show off your greater knowledge, rather use it to help solve
  the problem.
• Keep a log of the calls.
• If caller is unknown to you, determine health worker’s level of knowledge and
  clinical HIV/AIDS experience (clinical officer, medical aide, nurse, nurse-midwife,
  nurse practitioner, specialist, pharmacist, etc.)
• Understand what the questions are by repeating them.
• Be brief as appropriate
• Limit recommendations or plan to five or less to improve compliance.
• Be specific and concise because key points can be lost in a mass of less important
  points.
• Studies indicate that compliance is improved if recommendations are specific
  especially for drug recommendations (dose, frequency, route, etc.).
• Respect your own limitations. If you are not familiar with the subject area and need
  to do research or get other opinions, it is appropriate to say so.
• If necessary, ask health worker to go back to patient, do a further physical
  examination or clarify the history, and then call you back.
• Give a timeline as to when you will be call back if this is necessary.
• Ask caller to repeat your recommendations. Clarify as necessary.
• Wish them luck with their patient and invite them to follow-up with you again as
  appropriate.
• Develop a list of FAQs (Frequently Asked Questions) with answers.
• Record call in the phone log.
EXERCISE 18-1

Role Play:

You will practice making and receiving calls to consult on patients presented in the following cases.

Case 1: 35 year old man on ART for one month (). He was on clinical stage 3. He was fine until a week ago. He has had fever, cough and difficult breathing for the past five days. Additionally he has not eaten well in the past couple of days since his wife has been sick as well and he has lost some weight. Also, he has some nausea and feels depressed. He is thinking that after all ART Is not so great. He is asking you if it is really necessary to continue these drugs.

Pertinent positives on clinical exam: lost kg since last visit (two weeks ago)
His temperature is 38
His breathing is 25 breaths/minute
He is on CTX

Information that needs to be given to the doctor:
Age, sex
Clinical stage at start of ART
ART regimen and duration of Rx
Other medication
Main complain
Pertinent abnormalities in physical examination and new lab test

Reason for calling:
What to do with these symptoms?
Stop or continue or switch ART?
What treatment to give?
Refer patient to the hospital?
**Case 2:** 25 year-old woman on ART for two months (d4T-3TC-EFV) is now pregnant. You suspect she has been pregnant for one month. Clinical stage 3 at start of ART. She has been taking CTX. She is concerned because she has not practiced safer sex and right now she has burning pain when urinating. Additionally, she has been having headache and nausea, especially in the morning. She has not told her husband yet and does not know what to do.

She has no vaginal discharge or genital ulcer. She is not aware of her partner having a urethral discharge.

**Information that needs to be given to the doctor:**
- Age, sex
- Clinical stage at start of ART
- ART regimen and duration of Rx
- Other medications
- Main complaint
- Pertinent abnormalities on physical examination and lab test

**Reason for calling:**
- Likely pregnant
- What to do with ART?
- Stop, continue or switch ART?
- Send patient to the hospital

**Case 3:** 40 year old man on TB treatment for one month (smear negative pulmonary TB). He has not been eligible for ART so far because no other signs of stage 3 were present. Now he has oral thrush. He has not gained weight on treatment and he has no cough and fever anymore. He is a businessman and you are concerned about his adherence. Additionally you are not completely sure if he practices safer sex. Sometimes he comes with an STI.

**Information that needs to be given to the doctor:**
- Age, sex
- Clinical stage at start of ART
- ART regimen and duration of Rx
- Other medications
- Main complaint
- Abnormalities in physical examination and lab test

**Reason for calling:**
- What to do about co-treatment?
- Start ART?
- Send patient to the hospital
Case 4: Consult with the district doctor on the following case:

Patient is a 27 year-old female who is HIV+ and was started one week ago at your health centre. She comes today complaining of a rash which started 2 days ago. She tells you that she tried a local remedy, a cream, but the rash seems to be getting worse. She says that she was reading her Patient Treatment Card and realized that she should come in urgently for a rash.

Medical History: HIV + (diagnosed 4 years ago)
Clinical stage 4
History of TB- completed treatment 1 year ago
History of recurrent herpes simplex
Episode of oesophageal thrush which resolved with treatment.

Medications: Cotrimoxazole 960mg QD (each day), started 4 months ago
(30/150/200) combined tab qAM (each morning)
  d4T 30mg each evening
  3TC 150mg each evening

Clinical Review: You circled these positives on your Clinical Review form:
+ new skin rash, + mild fever per patient, + diarrhoea for 5 days, + nausea. No cough, no night sweats, no STI signs, no mouth sores, no headache, no fatigue, no vomiting, appetite fair, no tingling/numb/ painful feet, no pain, no sexual problems.

Social History: Patient is married and does not have any children. She works at home in keeping the house. She tells you that she would one day like to have children if she feels better, but not right now. She and her husband do not use condoms, because he is HIV+ as well, so patient states that it really does not matter. Her husband just lost his job working as a clerk in a local business, because the business closed and is a bit depressed. They have enough food for right now but she does not know for how long. She worries that it may difficult to come to her appointments as she lives 25 km away.

Physical Exam: Weight 55kg (last visit 56kg), Temp 36.5C; On skin exam, there is a dry macular rash (pink spots) distributed evenly over chest and both upper arms. There appears to be some mild desquamation (sloughing) of dry skin. There are no vesicles (blisters), no ulcerations, no involvement of the eyes or mouth. The rash does not appear to be wet. The rest of the physical exam is normal.

Plan: You decide to phone the district clinician to ask for advice about the rash.

Prepare for the call then we will practice making it in class, using the facilitator as the medical officer.